

Open Research Online

The Open University's repository of research publications
and other research outputs

Can an Inclusive Approach Meaningfully Engage People with Learning Disabilities? Exploring Capacity Building for Citizen Science

Thesis

How to cite:

Carr, Jessica E. (2021). Can an Inclusive Approach Meaningfully Engage People with Learning Disabilities? Exploring Capacity Building for Citizen Science. PhD thesis The Open University.

For guidance on citations see [FAQs](#).

© 2021 Jessica Eira Carr



<https://creativecommons.org/licenses/by-nc-nd/4.0/>

Version: Version of Record

Link(s) to article on publisher's website:

<http://dx.doi.org/doi:10.21954/ou.ro.0001365a>

Copyright and Moral Rights for the articles on this site are retained by the individual authors and/or other copyright owners. For more information on Open Research Online's data [policy](#) on reuse of materials please consult the policies page.

oro.open.ac.uk



Can an inclusive approach meaningfully engage people with learning disabilities? Exploring capacity building for citizen science

Jessica E. Carr

Thesis submitted to the Open University for the degree of Doctor of Philosophy (PhD)

WELS

OpenTEL
The Open University

Submitted for examination: January 2021

Accessible abstract

Who are we?

The Banbury self-advocacy group are part of the Oxfordshire based charity, My Life My Choice. The group and Jess Carr worked together to do research into how people with learning disabilities do citizen science.

What did we do?

We made our own citizen science project about how to look after cats and dogs. We learnt research skills and then used these to complete our project. Jess Carr also wrote down what we were doing as a group and investigated how we did it. This was to let researchers who do citizen science know how to work with people with learning disabilities.

What did we find?

People with learning disabilities can do citizen science. Researchers need to adapt the way they do it.

What are the suggestions?

We have the following suggestions for researchers:

1. Help them/people
2. Give it a go
3. Support them
4. Talk to people

This thesis belongs not only to Jess Carr but also to the Banbury self-advocacy group.

Acknowledgements

This thesis would never have reached completion without the help of my wonderful support system.

When embarking upon a task as vast and terrifying as a PhD, you can only wish to have supervisors like I was lucky enough to have. Professor Jane Seale, Professor Richard Holliman and Professor Eileen Scanlon have been my mentors, provided me with strength when I thought I had none and guided me every step of the way. Thank you doesn't cover the gratitude I owe to each of you.

Next, I would like to thank Adam Roberts for believing in me on the days that I really didn't. Your love got me through what was (at the time of publishing) the toughest four years of my life. I would also like to thank my wonderful mother Dr Jenni Carr. You continue to be my daily inspiration. Of course, I can't forget my father Tony Carr for providing the laughs when I desperately needed them.

The IET PhD community have been there to push me through the most difficult days. They've been my shoulder to cry on, and the people whom I most love to celebrate with. Thank you.

I owe a massive debt to Ruth Shaw-Williams for believing in the crazy lady down the phone and sharing the passion I had for this form of work.

Finally, and most importantly, I would like to thank the Banbury My Life My Choice self-advocacy group. The work we created together has the potential to change the opportunities for many people with learning disabilities. Without you, that would never have been possible. Each of you is my hero.

Table of Contents

Accessible abstract	2
Acknowledgements	3
List of figures and tables	9
Chapter 1 – Introduction	10
1.1 Overview	10
1.1.1 Research Problem	10
1.1.2 Motivations	11
1.1.3 Aims and Objectives	12
1.2 Part One – Participation: The Common Thread	14
1.2.1 Identifying the gap	14
1.2.2 Citizen Science	15
1.2.3 Learning Disabilities	15
1.2.4 Inclusive Research	16
1.2.5 Capacity Building	17
1.3 Part Two – ‘Nothing about us without us’: Inclusive Research Design	17
1.3.1 Methodological Position	18
1.3.2 Use of Creative Methods	19
1.3.3 Research Design	19
1.4 Part Three – ‘Give it a go’: Supporting Capacity Building	20
Part One – Participation: The Common Thread	21
Chapter 2: Literature Review	22
2.1 Introduction	22
2.2 – Why is citizen science important?	23
2.2.1 – Public Engagement	25
2.2.2- Motivations	26
2.2.3 – Perceived benefits	29
2.2.4 – How, processes of citizen science	30
2.2.5 – Who engages in citizen science?	32
2.2.5.1 – Exploring ‘publics’	33
2.2.5.2 – Exclusion criteria	34
2.2.6 – Citizen Science projects and minority groups	36
2.2.7 – Summary	38

2.3 – Learning Disabilities.....	39
2.3.1 – Labelling.....	39
2.3.2 – Self-identity and citizenship	42
2.4 – Inclusive Research.....	43
2.4.1 Principles informing how inclusive research should be done.....	45
2.4.2 People with learning disabilities doing inclusive research	48
2.4.3 Summary.....	53
2.5 – Similarities and differences between citizen science and inclusive research	54
2.6 Capacity building.....	57
2.7 – Summary.....	59
Part Two – ‘Nothing about us without us’: Inclusive Research Design	61
Chapter 3: Methodology	62
3.1 Introduction	62
3.2 Methodological Position.....	62
3.3 Methods	67
3.3.1 Creative methods	68
3.3.2 Qualitative data collection methods.....	70
3.4 Research Context.....	73
3.4.1 Research design	73
3.4.2 Participants and setting	75
3.5 Data Analysis Methods.....	77
3.6 Reliability and validity	82
3.7 Ethics	87
3.7.1 Working with vulnerable adults.....	87
3.7.2 Addressing the issue of power.....	88
3.7.3 Informed consent	89
3.7.4 Research Data Management	89
3.8 Summary.....	90
Chapter 4 – Capacity Building Programme.....	92
4.1 Introduction	92
4.2 Phase 1: Building Capacity.....	92
4.2.1 Phase 1, Session 1: Collage Yourself	97
4.2.2 Sessions 2 & 3	98
4.2.3 Discussion of Phase 1 (Sessions 1 to 3).....	104
4.3 Phase 2 (Sessions 4-11): Planning and conducting the citizen science project	105

4.3.1 Introduction	105
4.3.2 Phase 2, Session 4: Planning & nQuire	114
4.3.3 Phase 2, Session 5: Research Plan.....	117
4.3.4 Phase 2, Session 6: Research plan and surveys	119
4.3.5 Phase 2, Sessions 7-10: Data analysis	120
4.3.6 Session 11: Completion.....	122
4.3.7 Summary of Phase 2 (Sessions 4-11)	123
4.4 Phase 3, Sessions 12 to 13: Evaluating our capacity	123
4.4.1 Interviews	127
4.4.2 My experience	129
4.4.3 Discussion of Phase 3	130
Part Three – ‘Give it a go’: Supporting Capacity Building.....	131
Chapter 5: Findings – Capacity	132
5.1 Introduction	132
5.2 Engagement	133
5.2.1 Fully engaged	133
5.2.2 Distraction	136
5.2.3 Interest in the task.....	140
5.2.4 Understanding of the task	141
5.2.5 Summary on engagement	142
5.3 Ability to recall.....	144
5.4 Advocacy.....	146
5.5 Agency.....	147
5.6 Intrapersonal	149
5.6.1 Non-disabled identity	149
5.6.2 Disabled identity	151
5.7 Literacy.....	152
5.7.1 Scientific literacy	153
5.7.2 Inquiry/Research literacy.....	154
5.7.3 Reading and writing literacy.....	156
5.7.4 Emotional literacy.....	157
5.7.5 Summary.....	158
5.8 Political capacity	159
5.9 Prior experience and knowledge.....	163
5.10 Self-advocacy	165

5.11 Discussion of Capacity	166
Chapter 6 – Support	170
6.1 Introduction	170
6.2 Non-disabled researcher	171
6.2.1 Ensuring the involvement of the co-researchers.....	171
6.2.2 Structuring	174
6.2.3 Personal Support.....	175
6.2.4 Prompting to focus.....	175
6.2.5 Technical aspects of the task	176
6.2.6 Summary of non-disabled researcher	177
6.3 Co-researcher.....	177
6.3.1 Confidence.....	178
6.3.2 Renegotiating (Dis)Ability	181
6.3.3 Helping others to engage	181
6.3.4 Leading decision making	182
6.3.5 Technical aspects of the task	183
6.3.6 Summary.....	185
6.4 Environment	186
6.4.1 Location.....	186
6.4.2 Number and nature of facilitators	188
6.4.3 Routines	188
6.4.4 Summary.....	190
6.5 Discussion of Support.....	190
Chapter 7 – Discussion and Conclusions	192
7.1 Introduction	192
7.2 Addressing the Research Questions.....	193
7.2.1 Research Question (a). How do people with learning disabilities understand research as a process that underpins citizen science?	193
7.2.2 – Research Question (b) Does a structured approach to capacity building support people with learning disabilities in their engagement with the research process?	200
7.2.3 – Research Question (c) Do methods derived from inclusive research support engagement for people with learning disabilities with citizen science?.....	203
7.3 The sum of the constituent parts	205
7.4 Practical suggestions.....	209
7.4.1 Research training	209
7.4.2 Technology	211

7.4.3 Group Work.....	213
7.5 Theoretical suggestions	213
7.5.1 ‘Inclusivity’ is key	214
7.5.2 Extending citizen science topics away from the ‘natural’ sciences.....	215
7.5.3 Questioning what is ‘citizen science’?	215
7.6 Key contextual factors	217
7.7 Co-researchers suggestions for citizen science researcher	218
References	221
Appendix A – Banbury My Life My Choice ‘Trifold’ Leaflet	235
Appendix B: HREC approval HREC/2958/Carr	237
Appendix C: Consent form.....	239
Appendix D: Information Sheet – Co-researchers.....	241
Appendix E: Information sheet – Parents and Guardians.....	244
Appendix F – Examples of offline resources	247
Appendix G: Reflective letter from MLMC staff member.....	248

List of figures and tables

Figure 1 - Relationship between research questions and key themes.....	13
Figure 2 - Critical Research Paradigm.....	18
Figure 3 - Arnstein's ladder of participation (1969)	55
Figure 4 - Exploring ideas about consent, using a flipchart.....	97
Figure 5 - An example of an Identity box.....	103
Figure 6 - nQuire Confidential Mission.....	114
Figure 7 - Co-researchers initial planning (Boxes added for anonymity)	116
Figure 8 - Research planning document (for co-researchers).....	118
Figure 9 - Interview Protocol	127
Figure 10 - Co-researcher's collages.....	134
Figure 11 - Identity Box.....	150
Figure 12 - Collage	151
Figure 13 - Notes on consent.....	156
Figure 14 - Co-researcher's levels of research.....	162
Figure 15 - P9 Photography	172
Figure 16 – Collage example (P2)	184
Figure 17 - My Life My Choice Agenda	189
Figure 18 - Co-researcher's suggestions.....	218
Figure 19 - Inclusive Engagement.....	219
Table 1 - Design of project.....	19
Table 2 - Outline of Phases.....	74
Table 3 - Analysis Introduction	81
Table 4 – Phase 1, Session 1.....	94
Table 5 – Phase 1, Session 2.....	95
Table 6 – Phase 1, Session 3.....	96
Table 7 – Phase 2, Session 4.....	106
Table 8 – Phase 2, Session 5.....	107
Table 9 – Phase 2, Session 6.....	108
Table 10 – Phase 2, Session 7.....	109
Table 11 – Phase 2, Session 8.....	110
Table 12 – Phase 2, Session 9.....	111
Table 13 – Phase 2, Session 10.....	112
Table 14 – Phase 2, Session 11.....	113
Table 15 – Phase 3, Session 12.....	125
Table 16 – Phase 3, Session 13.....	126
Table 17 - Capacity.....	132
Table 18 - Support	170

Chapter 1 – Introduction

1.1 Overview

1.1.1 Research Problem

In 2019, UKRI outlined their four aims for public engagement for 2019-2020:

1. “Everyone in the UK has the opportunity to participate in research and innovation.
2. Researchers and innovators know why, when and how to actively involve people in their work and are supported and incentivised to do so.
3. Young people feel empowered to participate in research and innovation across the arts, humanities, STEM and social sciences.
4. Society plays an active role in shaping the direction of research and innovation.”

(UKRI, 2019: p.33)

Now in 2021, this thesis asks whether there is more that those organising Citizen Science projects could be doing to fulfil the aim of being for everyone.

As more public funders begin to recognise the importance of public engagement with research (UKRI, 2019), this has an influence on science. In effect scientists continue to be asked to abandon the view that “science is an unashamedly elitist activity” (Durodie, 2003) and open their doors to those perceived to be to the ‘non-elite’. Yet, the literature identifies a gap in the current STEM climate (Section 2.2), whereby certain communities are not actively engaged. One of these is the learning-disabled community, removing their voices from this decision influencing practice. A large part of identity is the feeling of belonging within a community (Strnadova et al., 2018). The citizen science community appears to have ignored people with learning disabilities and therefore denied their membership from this community.

In this thesis I argue that if people with learning disabilities are to be fully included in society it is important for them to have meaningful opportunities to engage with relevant types of citizen science. As a result of this, I will refer to the contributors from My Life My Choice as ‘co-researchers’ throughout this thesis. This is a term found within the inclusive research literature that I argue highlights the importance of their role within the project. Furthermore, the term co-researcher identifies how each person played an independent part within the project and highlights the equality

between all partners within the research. Further, it is my contention that currently people with learning disabilities are excluded from meaningful engagement with citizen science.

When discussing citizenship, Allgaier (2010) implies that a citizen has the duty to participate in decision-making that will affect themselves and their society. This is what he calls a “scientific citizenship”, where citizens have the “right” and “duty” to engage with science and how it affects their lives. He also argues that it is a citizen’s responsibility to engage. Yet, he fails to mention citizens who may need support, for example marginalized communities including people with learning disabilities. Furthermore, he fails to discuss the “rights” and “duties” of science communicators. I argue that science communicators should ensure that all citizens can engage with science and to build their “scientific citizenship”.

Research within learning disability studies shows that when people with learning-disabilities are given help and an opportunity to be involved in the process, they demonstrate their capabilities (Wehmeyer, 2014: p.39). This highlights the importance of capacity building and identifies a gap in our understanding of citizen science. As such, I would argue that it is important that the citizen science community should explore the question of, what capacity building is needed to enable people with learning disabilities to engage in the decision-making process?

Having outlined the key principles underpinning this research problem, in the next section of this chapter I will discuss the motivations behind this research.

1.1.2 Motivations

My motivations in selecting this topic are both personal and professional. Before returning to higher education, I worked in the Oxfordshire-based learning disability charity ‘Yellow Submarine’ (www.yellowsubmarine.org.uk). I worked with both adults and young people with learning disabilities who participated in structured employment training schemes designed to prepare them for paid employment. This work allowed me to reflect on how this community had not been exposed to the same opportunities that I, as a non-disabled child, had been offered whilst growing up. Specifically, I noted opportunities that enabled me to engage in my citizenship rights and obligations, such as citizen science. I believe involvement in citizen science, specifically in the decision-making processes about policy issues that affect our lives, is a fundamental citizenship right. Furthermore, those developing/organising these initiatives should consider what is required to allow all types of people to participate. This influenced my aspiration to give a voice to people with learning disabilities,

something which is a central issue within this research project. From this aspiration I found an interest in the use of inclusive research techniques, focusing on their use to explore capacity building for people with learning disabilities within citizen science.

Prior to embarking on my PhD journey, I undertook a Masters in Research Methods. The topic of my dissertation was ‘How do people with learning disabilities understand citizen science?’ (Carr, 2018). The dissertation discussed how people with learning disabilities had the capacity to engage in scientific inquiry, yet more research was needed to be done to understand how practice needed to change to include them. The project introduced a group of adults with learning disabilities to citizen science, by following a plan like the one discussed in this thesis (Chapter 4). The participants of this project identified how their previous negative experiences of science effected their initial engagement in the research. The key difference of my master’s project and the project discussed in this thesis was time. The Masters project took place over six weeks, whereas the project discussed in this thedesis took place over 12 months. This was the starting point for this thesis and my PhD research.

1.1.3 Aims and Objectives

The literature surrounding inclusive research is vast, and within it there are many different sets of principles and ideals presented for researchers. My first objective for this project, was to synthesise this literature, identify the gaps and situate my research within them. I will discuss this further in my literature review (Section 2.4).

The second objective of this project was to negotiate access to a group of people with learning disabilities (Section 3.4.2). My Life My Choice (www.mylifemychoice.org.uk), provided an environment in which to do this, working alongside their self-advocacy groups. The rationale for choosing this particular charity was that they campaign for autonomy of their members (see for example: <http://www.justiceforlb.org>). The administrator of the self-advocacy groups (referred to as P11 in this thesis) had already been involved in inclusive research and understood the benefits that came along with this form of research.

The third objective was to facilitate the engagement of people with learning disabilities in engaging with capacity building and citizen science. To do this, I planned to use an inclusive approach and a combination of creative and traditional research methods to create a capacity building programme. In Chapter 4, I explain the process of working with people with learning disabilities in more detail.

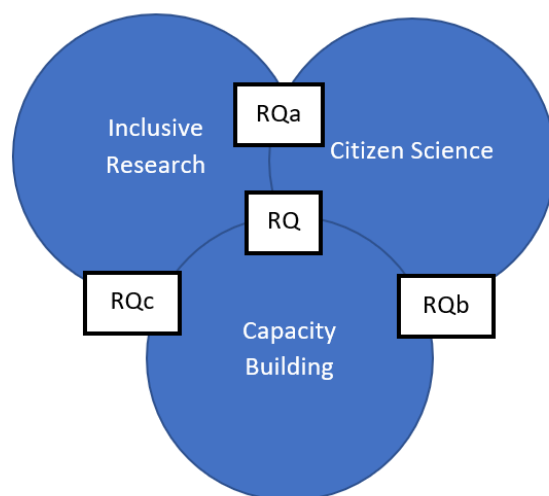
The fourth and final objective of this thesis was to contribute to the citizen science discourse by offering researchers within the area practical suggestions to inform their practice (Section 7.4).

This research project is focused on the question; What support do people with learning disabilities require regarding their capacity to engage with citizen science? This is further broken down into three questions focusing on the co-researchers' understanding of the research process, the value of structured support and the ability of inclusive research methods to support engagement.

- RQa. How do people with learning disabilities understand research as a process that underpins citizen science?
- RQb. Does a structured approach to capacity building support people with learning disabilities in their engagement with the research processes?
- RQc. Do methods derived from inclusive research support engagement for people with learning disabilities with citizen science?

Figure 1 illustrates how these questions connect to the three themes that underpin this project, inclusive research, citizen science and capacity building.

Figure 1- Relationship between research questions and key themes



The research questions were identified through my literature review, which I will discuss in more detail in Chapter 2.

Having outlined the aims and objectives of this project, I will now move on to introduce the three parts of this thesis:

- Part One – Participation: The Common Thread.
- Part Two – ‘Nothing about us without us’: Inclusive Research Design
- Part Three – ‘Give it a go’: Supporting Capacity Building

1.2 Part One – Participation: The Common Thread

1.2.1 Identifying the gap

Part one of this thesis is presented as the literature review. When beginning the literature review process Potter (2006) suggests that the writer must first identify the purpose of the review. For this thesis, the purpose of the literature review was to not only situate the planned research project but also to identify any gaps within the literature. The importance of identifying a gap lies in the potential to create new knowledge. This research project was aimed at breaking new ground within the fields of inclusive research, citizen science and public engagement, and capacity building. The literature review in Chapter 2 highlights how the three fields identified above all shared a common thread of ‘participation’, yet each differed in their approach to this. By identifying the gaps within the literature, this project could begin to create links between the three fields, potentially filling in the key gaps.

During the literature review process, I identified gaps within each field which could potentially be filled by using processes from another field. For example, research within learning disability studies shows that when people with learning disabilities are given help and an opportunity to be involved in the process, they demonstrate their capabilities (Wehmeyer, 2014: p.39). Wehmeyer’s study identifies how it is the role of the researcher to provide opportunities for engagement in the process. This identifies a gap in the design of many citizen science projects, where much of the literature suggests that responsibility for engagement, or indeed disengagement, lies with the participant, not the researcher. Furthermore, the literature surrounding the implementation of capacity building tools within inclusive research suggests how these can improve the engagement of the co-researchers. I argue that this improvement, conveys how, by using an inclusive approach to capacity building within citizen science, researchers can begin to engage a wider audience in their public engagement activities. I will now move on to discuss the different sections of the literature review, briefly introducing each topic and providing a short explanation as to the review’s findings.

1.2.2 Citizen Science

Citizen science is a form of research whereby professional scientists involve members of the public in scientific inquiry. The term ‘citizen science’ was used by Irwin (1995) and Bonney (2009) in the early 1990’s, but amateur involvement in science can be traced at least as far back as the eighteenth century (Vetter, 2011: p.134). There are many different motivations behind citizen science, but largely it is used to gather, analyse, and/or interpret data through a community of volunteers (Curtis et al., 2017). Similar to aspects of inclusive research, its participatory approach breaks down at least some of the barriers between ‘experts’ and ‘non-experts’ by opening up interactions between scientists and members of the public. As previously discussed, Allgaier implies that a citizen has the duty to participate in decision-making that will affect themselves and their society (2010). Yet, within his discussion, Allgaier fails to recognise the responsibility of the science communicators for engagement. This, I argue, creates a discourse within which marginalized communities are ignored as science communicators don’t take responsibility for their engagement.

In this thesis I will argue that citizen science, whilst having the *potential* to be inclusive, has yet to succeed in fulfilling this potential. The literature uses the terms ‘public’ to define those who engage in citizen science. This generalization does not include those currently not engaged, and the current discourse does not discuss how to approach these under-represented communities. The literature surrounding motivations to engage, whilst still developing, only adds to this issue. By offering a generalized view of those engaging in citizen science, it does not highlight who is under-served, and the reasons why these communities are under-represented.

1.2.3 Learning Disabilities

The term ‘learning disability’ is used to describe a community of people diagnosed as “hav[ing] difficulty, understanding new or complex information, learning new skills and coping independently” (Department of Health, 2001). Throughout history, societies have used many different labels to describe this community such as, ‘idiots’, ‘mentally retarded’ and ‘special’. Over time, these terms have been proved to segregate, demean, and demoralise this section of our society. Wilkinson (2005) describes how today, we still use the term ‘special’ when referring to education and health care. A term which has many negative connotations within society, and as Wilkinson explains, “actively encourages passive apartheid” (p.2) of this community. In this thesis I challenge these assumptions using the label ‘co-researcher’ to refer to the group of adults with learning disabilities who engaged with this project. Furthermore, the label ‘co-researcher’ aims to identify the equal power distribution

within the project whilst highlighting a group of people who have every right to be involved in the scientific conversations. It aims to remove negative connotations and instead create a safe environment for relationships between two different communities to grow.

In this thesis I will focus on key aspects of the learning disability literature: labelling; and self-identity and citizenship. By understanding the discourse around these terms, this project aims to provide the co-researchers with the appropriate groundwork to position themselves within the citizen science field.

One of the key devices through which I aimed to develop a space for engagement with citizen science was inclusive research. I will now move on to introduce this concept in the next section.

1.2.4 Inclusive Research

Inclusive research is a form of research which aims to break down barriers between ‘non-experts’ and ‘experts’ by involving the non-research community in parts or all of the research process. Nind (2014) describes it as “research that changes the dynamic between research/researchers and the people who are usually researched” (p.3). Using Kiernan’s (1999) “on/for/with” (p.43) approach to deciding methodology, inclusive research focuses its attention on being ‘with’ people with learning disabilities reflecting the popular disability motto “nothing about us without us” (Rix, 2006: p.161). Inclusive research is often focused on a diverse range of marginalised groups, but for the purposes of this project I will only be referring to it in the context of learning disability.

Inclusive research offers this community the ability to guide research with the aim of improving some aspect of their lives. Nind (2008) describes it as “research with, not on or for”, highlighting the participatory nature of these research methods (p.4). The participatory nature of inclusive research conveys the societal move from a medical model of disability, in which the community were treated as subjects or consultants, to the social model of disability research described by Oliver (1990) as research where this community are treated as equals. The underpinning argument for this shift is that impairment is socially constructed and can be removed through research which treats the participants, or ‘co-researchers’ as they are referred to in this project, as ‘experts’ in their community.

In the literature review I will discuss the processes of inclusive research, and the vast discourse surrounding these. Furthermore, I will highlight how inclusive research is adapting and shifting its focus to outcome over process. In this thesis I will argue that inclusive research is relevant for this project as it focuses on the importance of capacity building to increase the independence of people with learning disabilities within research. I will discuss this in more detail below.

1.2.5 Capacity Building

Capacity building within this thesis is used to explain the research skills training that took place during the physical study (Chapter 4). Prior to conducting the study, a review of the literature was undertaken to inform both the research design and the research practice with a view to reflexively building capacity for what was expected to be a diverse group of citizen scientists.

Strnadova et al. (2014) argue that in order to build a research team with people with learning disabilities, the trained and experienced researchers must adopt a supportive and capacity-building role to enable their co-researchers with learning disabilities to be fully involved and not just consulted. Their paper discusses how, through research skills training, “the researchers with intellectual disabilities began to contribute to the research with their own research agenda” (p.17).

In this literature review I will discuss how the capacity building discourse highlights the importance of valuing each individuals’ skills and knowledge, whilst offering opportunities to learn new skills. This was key to the project discussed in this thesis, as each co-researcher was given chances to explore new and current skills and share these with the rest of the group.

The literature on capacity building, influenced the programme discussed in Chapter 4. Through drawing on the literature, I was able to design and implement a programme that was reflexive and created an environment of learning which was key to the co-researchers’ engagement with citizen science.

Having discussed the different parts of the first part of this thesis I will now move on to introduce the basis for the second part of this thesis, focusing on the research design.

1.3 Part Two – ‘Nothing about us without us’: Inclusive Research Design

The second part of this thesis looks at the methodology behind the research project. Firstly, I will introduce the methodological positioning of this project and discuss the influence this had on the research process. Next, I will present the justification behind the use of creative research methods within this project. Finally, I will briefly introduce the research design.

1.3.1 Methodological Position

Kiernan (1999) identified how research can be “on/for/with” people (p.43). This project aimed to conduct research “with” the learning-disabled community and to argue that the exploration of research “with” needs to be more inclusive. This approach is often linked with a critical research paradigm (Cohen et al. 2000: p.35), a paradigm which has had an impact on this study. The critical paradigm is outlined below in Figure 2:

Figure 2 - Critical Research Paradigm



The critical research paradigm is defined through its focus on inequities, and it's use of “participant researchers” (Cohen et al. 2000 p.35). This provides a clear link to inclusive research and its focus on research ‘with’ its research subjects. Having briefly introduced the methodological position of this project I will now move on to discuss the creative research methods employed in this project.

1.3.2 Use of Creative Methods

Creativity as a term is hard to define (Kara, 2015). In research we use it to describe work that is done outside of ‘traditional norms’. In this project, I use the term creative to refer to arts-based methods. My rationale for using this approach lies within their ability to be adapted, in effect, to suit the needs of different participants. Biggs (2009) identifies how artwork can be defined as a research output, “so long as they are regarded as embodying new knowledge or improved insights” (p.67). The artworks created in this project, are classified as outputs of the data collection, and provide vital insights into the co-researchers’ understanding of research.

The creative methods in this project were employed in the first phase of the three-phase project outlined below (Table 1). The reasoning behind this was to allow the co-researchers to express themselves comfortably without having to use words. Furthermore, it created an environment of fun from the first session and many of the participants expressed how these sessions were in fact their favourite.

I will now move on to present the research design, discussing the justification for the choices made during the design process.

1.3.3 Research Design

This project was designed in three parts. I have provided a table to describe each phase below:

Table 1 - Design of project

	Phase 1 - Building capacity	Phase 2 – Planning and conducting the project	Phase 3 – Evaluating our capacity
Aim	Providing the groundwork for the co-researchers to enable them to conduct their own research project	The co-researchers planning and conducting their project, whilst evaluating their capacities to do so and the level of support required to enable them to do so independently	The co-researchers self-evaluate their capacities and reflect on their experience
No. of sessions	3	8	1 (3 were originally planned)

Data collected	Artefacts, audio recordings/transcripts, photographs, and observation notes	Audio recordings/transcripts
----------------	---	------------------------------

This project was designed to provide the co-researchers with sufficient time to learn and practice new skills. (Hence, the number of sessions in each Phase was flexible). The first phase provided the groundwork for the co-researchers to collectively define research. This was then carried through into the second phase where the co-researchers were able to learn and put into practice research skills in a supportive environment. The third and final phase of this project was designed to offer a reflective space for the co-researchers to discuss their participation within this project. However, when we were entering the third phase of research the world was struck with the Covid-19 pandemic which restricted progress. This meant that the research design had to be adapted to reflect this, whilst still allowing the co-researchers to express their opinions on the project. I will discuss this in more detail in Chapter 4.

1.4 Part Three – ‘Give it a go’: Supporting Capacity Building

The third and final part of this thesis looks at the findings of this project and offers suggestions for citizen science and future research into this research topic. The co-researchers in this project were asked to provide their own advice to future researchers. I will discuss the findings in more detail in Chapters 5 and 6.

In 2005, Morris questioned whether in 15 years’ time, disabled people would have the same opportunities as their non-disabled counterparts to “participate and contribute as equal citizens” (p.40). This thesis aims to address whether this statement has come to fruition, and more importantly if not then how do we as the research community need to adapt to make it so.

Part One – Participation: The Common Thread

Chapter 2: Literature Review

2.1 Introduction

Before presenting the literature, I would like to provide some background. A key assumption before this project was started was that citizen science is of relevance to the learning-disabled community. Secondly, my working hypothesis was that those organising citizen science initiatives had overlooked and under-represented this community from its practice. Initial searches of the literature supported this working hypothesis, i.e. that people with disabilities appeared to be absent from the citizen science discourse. These assessments highlighted a theoretical question and identified a practical challenge. Could people living with disability participate in citizen science projects? How might the learning-disabled community be supported in these activities? In this thesis, I argue that by using different methods, people with learning disabilities can and should be supported to engage in citizen science activities.

In exploring these issues, I developed a strategy to explore relevant literature from a number of different academic fields. By highlighting key words from key literatures (i.e. participation, inclusion, creativity), I then moved on to read through abstracts and decide which literatures would be relevant to this review. Here I will present selected literature within the fields of citizen science and public engagement, learning disabilities, inclusive research, and capacity building. The literature presented in this thesis was selected by judgements about the significance within the relevant fields. The three fields mentioned above were chosen for the focus of this literature review as I identified them as key to the project discussed in this thesis. The literature presented herein represents key texts that shaped and framed the research, both theoretically and pragmatically. Through the discussion of the literature I aim to provide a justification for my research and convey the gaps within the literature where my research is situated.

In Section 2.2, I discuss the question, why is citizen science important and what do we need to understand when engaging people in citizen science? Next, I will discuss the different processes of citizen science which are presented within the literature. Lastly, I will discuss who engages in citizen science, looking at the different descriptions of the involved parties within the literature. Furthermore, I will look at the issue of exclusion from citizen science and whether this activity routinely excludes certain communities.

In Section 2.3 I review the literature which discusses people with learning disabilities and their citizenship. Firstly, I will look at the sociological concept of labelling, and the processes which stigmatise people with learning disabilities. I will then look at self-identity and citizenship. I will introduce self-advocacy and look at identity literature to highlight the ability of this community to create and challenge discourse.

In Section 2.4, I will move on to review the inclusive research literature. I will begin by defining inclusive research. Firstly, I will look at how inclusive research is done, and the literature which presents this. Secondly, I will look at specific examples of people with learning disabilities doing inclusive research. Next, I will discuss the similarities and differences between citizen science and inclusive research.

Finally, in Section 2.5 I will review the literature around capacity building and research training, focusing on studies which were inclusive in nature. I will present the arguments for capacity building and discuss how the challenges these arguments pose for citizen science and its exclusion of certain communities.

2.2 – Why is citizen science important?

Citizen science was discussed in the 1990's by Bonney (2009) in the US context and Irwin (1995) in the UK, yet the field's origins lie far beyond when it was named. Vetter (2011) describes how "lay participation in scientific observation" (p.134) has occurred since the eighteenth-century citing examples, such as a Norwegian bishop who used clergy to further his research. Miller-Rushing et al. (2012) discuss how citizen science's history likely spans as far as the seventeenth century when science introduced some of the key institutions and practices that contributed to shape it today (p.286) such as, the establishment of the Royal Society by King Charles II in 1662. However, this sparked a series of processes that led to the professionalisation of researchers, and in which production of knowledge required expertise. Citizen science, as we know it today, is a way in which to blur this mode of knowledge production.

In more recent times online citizen science projects, such as iSpot (<https://www.ispotnature.org>) and GalaxyZoo (<https://www.zooniverse.org>), have used technological advances to reach more distributed publics and engage with them. Holliman and Curtis (2015) identify a trend within the increasingly ambient and ubiquitous 'digital landscape' of using mobile computing devices to increase the possibilities for citizen science projects. But are these projects routinely adapted for publics with

different needs and capacities; is citizen science open to all? This thesis will aim to use an online citizen science platform (www.nquire.org.uk/) to engage the co-researchers and identify their opinions and capacity regarding the use of technology.

Costello (2017) says that “asking what citizen science is, is like asking what art is” (p.18). By this he is referring to the broad range of approaches that are described as citizen science. For example, the Natural History Museum (2019-2020) advertised their project ‘Star Spotting Experiment’ as an opportunity for the public to ‘contribute data’ for a European wide project. This is quite a hands-on project for citizens to be involved in, where citizens partake in the making of data collection equipment, collecting the data, and submitting the data. There are different levels of participation in the processes of scientific investigation. Differing from the Natural History Museum experiment is Sci-Starter’s (n.d) project where citizen scientists need to take a ‘selfie’ of themselves next to a stream and provide basic information. These two citizen science projects are used as examples to show the differing levels of participation in citizen science.

The Citizen Science Association (CSA) offer a definition of citizen science on their website which looks at the different types of scientific investigations found within citizen science; “community driven” and “global investigations”. While this does not cover the wide span of citizen science studies, it does offer a quick insight into what citizen science is and the sort of work it does such as being focused on communities and investigating on a wider, global scale. The CSA (2018) also highlight the participation aspect of citizen science stating that “citizen science is the involvement of the public in scientific research”. The question is whether a broad theoretical conceptualisation of the terms ‘community’, ‘public’, or ‘citizen’ are sufficient to ensure that diversity is supported in how different communities, people and citizens have genuine opportunities to participate in these activities.

Citizen science is used in many different academic fields and because of this has many different descriptions. Kennedy (2016) chooses to describe it simply as “public engagement in scientific research and decision-making” (p. 21). Whilst this description highlights what citizen science is at its most basic, it misses the complexities surrounding the different motivations behind citizen science for both scientists and members of the public.

Similarly, Dickinson et al. (2012) offer a very simplistic description of citizen science describing it as “public participation in organized research efforts” (p.1). Havens and Henderson (2013) offer a similar definition, expanding it to describe the different types of people involved and why citizen science is used. It “empowers people from all walks of life to participate in the scientific process and help

advance knowledge in a wide range of scientific disciplines” (p.378). These definitions highlight that whilst the descriptions may differ, the heart of citizen science is ‘public engagement’. This is a theme found throughout all the definitions presented above. ‘Public engagement’ or ‘participation’ feature heavily in each definition. Whilst the particulars around how the projects are done may change, public participation is what makes an inquiry citizen science. Furthermore, Havens and Henderson’s (2013) definition highlights the ‘empowering’ possibility of citizen science which will play a key part in this project.

2.2.1 – Public Engagement

Public engagement is a relatively new term in the academic literature. It emerged in response to the influential House of Lords Select Committee Report (2000). Since then, it has been actively debated by academics and policy makers, resulting in what is currently promoted by UK research funders as a more progressive vision for public engagement (Holliman, 2019). This is illustrated by the 2019 UKRI (UK Research and Innovation) Delivery Plan where they set out four goals for public engagement:

1. “Focus on under-represented communities and places
2. Actively involve people in their work
3. Inspire and empower young people
4. Listen to and understand public concerns and aspirations”

(UKRI, 2019)

These goals highlight the importance of citizen science within research, as it opens doors to allow researchers to engage with different publics. Furthermore, the UKRI goals acknowledge that the aims of citizen science projects may not be to produce new knowledge. Instead, it can be used as a tool for connection and communication with members of the public. Yet, whilst the current discourse on citizen science conveys the importance of engaging with citizens, it does not discuss how this field of inquiry might benefit from “focus[ing] on under-represented communities and places” (UKRI, 2019). These discussions need to be had in order to involve previously ignored communities, such as the learning-disabled community, a dialogue which I have identified does not exist within current citizen science literature.

It is important, at this point, to highlight an historical injustice. Walmsley & Johnson (2003) discuss how people with learning disabilities have been used as the ‘subjects’ of research studies in the past

(p.10), and not actively involved in research. This thesis seeks to explore these issues, providing researchers using citizen science with an example of how to involve under-represented communities.

UKRI's four goals for public engagement offer a welcome direction of travel. Whether these will motivate researchers in the way they engage with diverse members of the public in future research remains to be seen.

2.2.2- Motivations

In this next section, I will look at the motivations discussed in the citizen science literature and how these have influenced my research.

This project investigates what support is required for people with learning disabilities to engage with citizen science. A large part of this, is understanding what motivates different participants to engage. Cappa et al. (2018) split motivations for engagement into two categories; intrinsic and extrinsic (p.247). Intrinsic motivation is described by Cappa et al. as being linked to “self-determination in participating”, based on their personal satisfaction and educational opportunities. Extrinsic, is described as focusing on the “intention to contribute based on some reward” (p.247). Jones, et al. (2018) further this categorisation of motivation by introducing, “altruism” (p.289). Jones et al.'s category of ‘altruism’ introduces the idea that those participating in citizen science do not actively seek any form of compensation, instead just an interest and desire in helping others may be enough to motivate potential participants.

Batson et al., (2002) add another dimension to a consideration of motivations by introducing the pragmatically informed concept of ‘principlism’:

1. “Egoism - citizen scientist's own welfare
2. Altruism – others welfare
3. Collectivism – a group's welfare
4. Principlism – upholding a moral principle”

(Batson et al., 2002. Taken from Land-Zastra et al. 2016: p.47)

The first of these categories “egoism” is a broader approach to Cappa et al.'s (2018) categories of ‘intrinsic’ and ‘extrinsic’, highlighting how a person might be motivated based on the different rewards they can gain personally. Batson et al.'s (2002) categories identify a desire to not only gain

reward personally or through helping another group, but a wish to keep and/or progress one's own morality. I argue that in the context of citizen science, one of these 'moral principle[s]' is that all citizens should have meaningful opportunities to engage in scientific inquiry.

The emphasis here being that the opportunities must be beneficial to all parties to ensure that benefits are more distributed. By aiming for distribution to as many publics as possible, we can hope to reach enough citizens to spread the benefits evenly. The categories also show links to Osborne's (2010) motivations to become involved in science communication.

Both Batson et al. (2002) and Osborne (2010) focus on the importance of sharing knowledge for specific reasons. The difference here is that Batson et al. (2002) focus on the concept of welfare within motivations and who's welfare a citizen scientist might focus on as most important to them.

Osborne (2010), when discussing science education, highlights four arguments for the dissemination and teaching of scientific knowledge: utilitarian, economic, cultural and democratic. Each of these highlight a different reason for doing science. Utilitarian focuses on the practical benefits of learning science whereas economic highlights the importance of scientists to "sustain the economic base" (p.49). Cultural is based around the idea that science is a large part of our culture and democratic views the importance of learning science through the impact science has on our societal issues. Osborne's arguments differ from Batson et al.'s (2002) focus on welfare by discussing the broader picture. The sharing of knowledge, through Osborne's arguments is beneficial on a more global context. Whereas Batson et al.'s (2002) other categories; Egoism, Altruism, Collectivism and Principlism, explore the importance of welfare as a motivation for engagement, focusing on the different groups who may participate in such activities i.e. communities and citizen scientists. When looking to engage in a research activity, particularly a public engagement based one, participants will weigh up the potential benefits from these categories and participate based on their belief that the project fits into one of Batson et al.'s aforementioned categories; egoism, altruism, collectivism and principlism.

Motivation can change over time. Within the literature, motivations for participation are organised into two categories; motivations for initial participation and motivations for longer-term participation (Rotman et al. 2014; Curtis 2015 (a); Jennett et al. 2016). One of the most common motivations, as identified by Curtis (2015 (a)), for both initiating participation and sustaining participation is the opportunity to "make a contribution". This identifies the importance to participants of being a part of the scientific and research communities. Furthermore, Rotman et al., (2014) suggest that personal

interest is a key component to the participant's initial participation. Without this, citizens are unlikely to join a citizen science study, or sustain their participation.

Another key motivation for initiating participation of citizen science projects, is an interest in science (Jennett et al. 2016; Land-Zastra et al. 2016; Jones et al. 2018; Curtis, 2015(b)). In Land-Zastra et al.'s study (2016), they asked respondents to score the applicability of statements to their own reasons for participating in citizen science studies. The component analysis conducted on the data collected identified how an interest in science was the second highest reason behind the participant's motivation to engage. Second only to a wish to contribute to scientific knowledge (p.51). Similarly, Jennett et al. (2016) identify how within their study, the participants' identified three key reasons for their initial motivation to engage with citizen science: "curiosity, interest in science and desire to contribute to research" (p.7). These studies identify how publics are motivated to engage with citizen science projects due to a pre-existing interest in science. This is often accompanied by some knowledge and understanding of the topic. Two key questions for the project discussed in this thesis are: what levels of scientific literacy are required to conduct citizen science research; and how might people with disabilities be supported in building capacity to participate?

When looking to understand why citizens engage in citizen science, it is also important to look at the reasons why 'experts', i.e. researchers, would aim to engage people with learning disabilities in their citizen science study. Firstly, one key benefit of conducting a citizen science study is the engaging of those who have 'first-hand' experience of the issue. Yet, citizen science studies are frequently created to research into topics of importance to scientists (i.e. GalaxyZoo – classification of celestial objects). This may mean that certain communities, such as people with learning disabilities, do not have 'first-hand' experience. Toerpe (2013) identifies a need for more researchers within the scientific community, but the citizen science literature fails to highlight the importance of topic choice. More needs to be done, to include a community who have previously not been engaged. By using an inclusive approach to the citizen science planning process, this research aims to answer that call. Furthermore, the learning-disabled community have different experiences of life to other non-disabled researchers. By including their narrative in our research studies, we are bringing in different viewpoints and opening up the scientific community to further discussions and different opinions. To use Irwin's (2008) theoretical concept of third-order engagement, "heterogeneity, conditionality and disagreement [should be seen] as a societal resource" (p.208).

Within the literature on motivations to participate within citizen science, there is nothing relating to the motivation of different communities to participate. There is no literature about those who may be typically excluded, for example, people with learning disabilities. Returning to the UKRI's (2019) goal of engaging previously under-represented communities in research, discussions about motivations for these communities are key to understanding how we as researchers can engage these communities in scientific inquiry.

2.2.3 – Perceived benefits

One key motivation discussed above is the benefits to people engaging in citizen science. I will discuss this in this section.

Within the many definitions of citizen science, the benefits for both the participants and the main researchers engaging in the research, are often highlighted. Brossard et al. (2005) described citizen science as focusing on the “public-professional partnerships that give individuals of all ages an opportunity to participate in real scientific research and to interact with scientists in the process” (p. 1101). This definition describes the participation found in citizen science, yet still avoids the question as to whether, in practice, this could be inclusive.

Brossard et al. (2005) highlight how the ‘public’ and the ‘professional’ are different, creating a barrier between the two groups. Furthermore, these two terms create wider gaps between the two groups by only highlighting the benefits to the ‘public’ and the not the knowledge exchange that could happen in the process. This automatically creates a power difference between the two groups and suggests that only scientists have knowledge worth sharing.

Furthermore, Toerpe (2013: p.25-27) discusses three different parts of what citizen science is:

- “1) Answers the scientific community’s need for more researchers.
- 2) Focus on science as crowd-centred and open-sourced.
- 3)Citizen scientists benefit from knowing they have helped advance scientific research and knowledge in a field they’re passionate about.”

The focus in Toerpe’s definition is on how the citizen scientists can benefit from engaging with professional scientists. Again, the focus is on the perceived benefits to the ‘public’ and avoids the discussion of how by engaging these communities research and researchers alike can benefit from a

form of knowledge exchange. This project aims to convey the importance of this exchange and look at the benefits of engaging under-represented communities.

2.2.4 – How, processes of citizen science

As discussed above, citizen science is conducted in many ways, whether this be through citizens taking photographs, downloading software onto their computer, or partaking in a study of the stars (Holliman and Curtis, 2015). When conducting this literature review, I aimed to discover definitions and principles that provided descriptions of ‘how’ to conduct citizen science. This would offer some insight into whether people with disabilities are explicitly or implicitly represented in these definitions.

OpenScientist (2018) offers a description of the citizen science research process:

“The systematic collection and analysis of data; development of technology; testing of natural phenomena; and the dissemination of these activities by researchers on a primarily vocational basis.”

Whilst this definition offers a perspective on process, it has two key problems. First, it fails to adequately define who could be a citizen scientist. It does not consider the diversity of potential contributors. Second, the definition omits some of the key aspects of citizen science, such as distributed collaboration. Instead, it offers a description of key aspects of a ‘typical’ research study. As OpenScientist classifies itself as a forum for “projects and opinions from the world of Citizen Science”, by not providing a clear description of the contributions of citizen scientists in the process of knowledge production, it overlooks the complexities of their participation. By having no mention of the collaboration and participation aspects of citizen science, a researcher using this forum as their guidance might not see the full potential of citizen science. Furthermore, the OpenScientist definition highlights how citizen science is a “vocational” activity for researchers, suggesting that researchers only conduct research to further their work-based objectives. This definition ignores the possibility that researchers may conduct citizen science for personal interest instead of just to further their career.

When researching the literature around citizen science I found very few principles for citizen science, unlike other research approaches such as inclusive research which I will discuss later in this chapter. Whilst definitions help us to understand what a field of research is, principles help to inform researchers’ practice.

One exception is the European Citizen Science Association (ECSA), which produced ten principles for good practice when conducting citizen science:

1. “Citizen science projects actively involve citizens in scientific endeavour that generates new knowledge or understanding.
2. Citizen science projects have a genuine science outcome.
3. Both the professional scientists and the citizen scientists benefit from taking part.
4. Citizen scientists may, participate in multiple stages of the scientific process.
5. Citizen scientists receive feedback from the project.
6. Citizen science is considered a research approach like any other, with limitations and biases that should be considered and controlled for.
7. Citizen science project data and meta-data are made publicly available and where possible, results are published in an open access format.
8. Citizen scientists are acknowledged in project results and publications.
9. Citizen science programmes are evaluated for their scientific output, data quality, participant experience and wider societal or policy impact.
10. The leaders of citizen science projects take into consideration legal and ethical issues surrounding copyright, intellectual property, data sharing agreements, confidentiality, attribution, and the environmental impact of any activities.”

(ECSA, 2015)

These principles offer insight into how a citizen science project should be conducted. They highlight aspects of citizen science research ranging from why people do it to more academic issues such as, legalities surrounding copyright and ethical issues. Furthermore, the principles demonstrate how citizen science as a field is maturing and moving towards a place where there are expected standards for researchers to follow. However, these principles fail to adequately define who could be a citizen scientist. Whilst there is greater acknowledgement of the contributions of citizen scientists, the principles do not consider the diversity of potential contributors.

This thesis will address one of the key shortfalls in these definitions and principles. It starts from the principle that citizen science should be available to all and explores how this can be operationalised with one community, citizen scientists with learning disabilities. I will provide a description of the process undertaken when conducting a citizen science study with a group of adults with learning

disabilities in Chapter 4. The research will extend the definition of citizen science to include diversity and inclusivity, and adapt the principles described above to include an inclusive approach.

2.2.5 – Who engages in citizen science?

The previous section has highlighted a key issue with definitions of citizen science, i.e. the failure to consider issues of inclusion. Silvertown (2009) describes citizen science as a form of science “potentially available to all, not just a privileged few” (p. 467), challenging the idea that “science is an unashamedly elitist activity” (Durodie, 2003: p.83), and highlighting the attempts to widen participation within citizen science. The question is whether this has been enacted in practice, or whether it is merely theory.

Ruiz-Mallen et al. (2016) discuss how citizen science aims to “reduce the remaining distance between lay people and science” by “providing opportunities for education and communication” (p.523). The term “lay-people” provokes the idea of someone who is untrained and non-qualified. It is a blanket term for non-experts. It denotes a person who is less experienced and therefore has less knowledge than that of an expert. As discussed for previous definitions, this creates a power difference between the citizen scientists and those who are described as experts. Demarcating expertise in this way creates a less inclusive environment, where different forms of expertise and skills are not necessarily valued equally. It has the effect of increasing the “remaining distance” between citizen scientists and professionals.

In countering these arguments, Irwin and Wynne (1996) states that ‘lay-people’ have an unrecognised ability to be reflexive and “develop their own social position” in response to scientific expertise (p.43). This reflexive capacity is proof of their ability to engage with forms of ‘scientific’ inquiry, and moreover, proof of their ability to adapt to their social conditions. A further key problem with the argument made by Ruiz-Mallen et al. (2016) is that the term ‘lay-people’ makes the assumption that members of these communities are a part of “a homogenous mass” (Irwin & Wynne, 1996: p.9), and do not represent the diversity found within each different community. My research starts from the perspective that different citizens and communities bring expertise and skills to citizen science. The key issue that this research addresses is how to identify pre-existing expertise and skills and build capacity, where needed, for citizen science to be more inclusive.

Ruiz-Mallen et al. (2016) also offer a second definition, which focuses on the benefits of doing citizen science for both parties involved, “A win-win situation where citizens are offered the possibility to contribute to scientific research projects *designed by professional researchers*” (p. 524).

Again, this definition highlights the idea of benefits for both academic researchers and members of the public, whilst creating separation between ‘citizens’ and ‘professional researchers’. This research furthers this, by highlighting the importance of not grouping all communities as one ‘public’. Williams (1989) identifies how there is no such thing as a mass, instead just “ways of seeing people as masses” (p.11). This conveys how, within citizen science, we should not take one approach to engage different communities as people are not one ‘mass’. Instead, by exploring the different forms of citizenship and community, and requirements for people to participate, we can fulfil the UKRI’s (2019) vision for public engagement and genuinely and meaningfully engage wider communities with research.

2.2.5.1 – Exploring ‘publics’

In Section 2.2.1, I discussed *why* people engage with citizen science. Here I ask *who* engages in citizen science.

Bonney et al. (2009) describe citizen science as “a research technique that enlists the public in gathering scientific information” (p.977), focusing on how scientists engage the public as fellow researchers to enable them to gather more data. In this definition ‘the public’ refers to non-experts. However, without providing a more in-depth definition of this phrase it raises the question as to whether ‘the public’ is all citizens, and whether everyone can participate. I argue that the broad nature of this term has the potential to create an invisible barrier to community groups who may not describe themselves as the general public; instead, citizens may identify through different more independent terms. I discuss this in more detail in Section 2.3.1.

Silvertown (2009) discusses two of the motivations behind citizen science and why scientists and members of the public do it: “Projects that may have been specifically designed or adapted to give amateurs a role, either for the educational benefit of the volunteers themselves or for the benefit of the project” (p.467). The language used within this quote creates a power difference between those who have “designed” a project, and those who are merely given “a role”. By suggesting that the only people who can benefit educationally from this collaboration are the “volunteers”, Silvertown ignores the potential for upstream (and downstream) knowledge sharing between those involved in the projects (Wilsdon and Willis, 2004). In other words, if researchers consistently follow this line of argument,

citizens only have a partial role in the research process, one that is defined and limited outside of their control. This only adds to the negative discourse in citizen science for people with disability, creating power boundaries between those considered ‘expert’ and those considered ‘amateur’ citizens.

These vague descriptions of ‘publics’ do not specifically exclude under-represented communities, but neither do they explicitly include them. In effect, the barrier to participation, as similar instances of exclusionary practices of museums suggest, is invisible (Dawson, 2018). Whilst the descriptions of publics and citizens are vague, they create barriers by assuming a lack of knowledge from these individuals and groups. In effect, however, it is the lack of knowledge of these groups by experts, and a commitment to adapt the practices of citizen science to be inclusive that are key underlying problems. There is no discussion of the knowledge exchange between publics and ‘experts’, instead the focus is on the education which working with ‘professional’ scientists can provide. This lack of conceptual understanding, allied with little effort to explore differences in publics, provides some insight as to why under-represented groups are routinely excluded.

By discussing the exclusion of different communities, we can begin to understand the importance of their inclusion and discuss whether the needs of the different groups should be considered when creating future citizen science projects. I will now move on to discuss other ways in which communities are excluded by citizen science.

2.2.5.2 – Exclusion criteria

When talking about citizen science, Irwin (1995) discussed how people are excluded from citizen science and therefore deprived of opportunities to engage. One key part of this, is a participant’s scientific literacy i.e., their knowledge of science, its processes, and its products. Allgaier (2010) argues that citizens must be exposed to scientific inquiry, such as citizen science, to gain “scientific citizenship”. As mentioned in Section 2.2.1, scientific literacy is often seen to be a key component to initiating participation in citizen science. In my Masters project (Carr, 2018), I highlighted how just the word ‘science’ acted as a negative trigger for some people with learning disabilities. Negative experiences from their education meant that the participants of my project, were less likely to want to engage in scientific inquiry. This hinders their ability to see any value in gaining ‘scientific citizenship’. Without the scientific community acknowledging that this is an issue and aiming to build confidence and self-efficacy among citizens and groups who may already feel excluded, it will be difficult to fulfil the potential for citizen science to be ‘for all’. Whilst this provides one example of the

exclusion of people with learning disabilities from citizen science, this thesis will aim to better understand the many other ways in which people with learning disabilities are excluded.

In my Masters project, I found that my participants with learning disabilities would self-exclude from the project due to their negative previous experiences of science, such as during school (Carr, 2018). This links to Allgaier's (2010) discussion of the "self-selection process" (p.132). He claims that participants will exclude themselves if they do not already have an interest in science. I argue, that in addition to this, participants will exclude themselves due to their previous experiences with science, e.g., if people have been excluded previously, if their needs have not been effectively supported to participate in science, or if they have been treated as the subjects of scientific experimentation in the past and not active participants. Previous research by Archer et al. (2013-2018) highlights the importance of "science capital" a term described by Godec, King and Archer (2017) as including "science-related knowledge (what you know), attitudes (what you think), experiences (what you do) and contacts (who you know)" (p.7). Public engagement strategies are increasingly using the concept of 'science capital' and highlighting the importance of building it within different communities to increase engagement (STFC, 2016). Whilst the research discussed in this thesis is in the same broad area of interest, it does not follow a science capital approach. This is where my research is broadly situated, studying what support is required to motivate participants with learning disabilities to engage and sustain their involvement.

In his discussion of scientific literacy, Durant (1994) argues that "scientific literacy should not be taken to mean the knowledge of a lot of science, but rather the understanding of how science really works" (p.83). This includes, for example, an understanding of the processes of science and how science is reflected in real world situations. Durant's description offers a more holistic and authentic view of science. It makes visible how science works in practice in different disciplines as a human activity. However, it is important to note that the emphasis on practice over theory also has the potential to create elitism by classing one (practice over theory) as more important than the other. Instead, I argue that by widening the definition of "scientific literacy" to include those who have both, or either, an understanding of the practical and theory of science therefore being more inclusive of different communities.

In this thesis, I will follow Durant's (1994) definition, by focusing on the co-researchers' understanding of 'how science really works', rather than focusing on their prior knowledge of science. This definition is less exclusive to those who have been given plenty of opportunity to gain scientific

knowledge, instead including those who may engage with science in broader settings. In other words, those engaging get to create and reframe their experiences of science through doing it.

There are two different views to the scientific elite involved with citizen science. Silvertown (2009) identifies how citizen science has the potential to be ‘for all’, removing the idea that science is for the elite (Durodie, 2003: p.83). Two questions for my thesis that follow are: has this potential been realised for people with learning disabilities in the past; and what measures can help to build capacity for people with learning disabilities in the future? The first of these questions will be answered in the summary of this chapter, the second will be addressed through the capacity building programme used in this thesis.

Another form of exclusion within citizen science is related to the digital divide. As identified earlier in this chapter, citizen science is progressively moving to be more online (Holliman and Curtis, 2015). An example of this is the iSpot (www.ispotnature.org/) platform developed by the Open University. The online platform encourages citizen scientists to engage by taking photos of wildlife, posting these on online forums and engaging in discussions with other users. This involves not only first accessing the online platform, but also the use of a camera, transferring of photos, uploading these, and then engaging on forums. Tasks such as these which may seem simple to those with technological experience, may be enough to exclude those with less experience. The digital divide focuses on the division and exclusion of certain community groups due to their access to and understanding of technologies (Ragnedda & Muschert 2013; Warschauer, 2003; Seale, C. et al., 2010; Selwyn, 2006). This exclusion has links to pre-existing social inequalities, where those who are commonly socially excluded are further affected by the ‘digital divide’. Seale & Chadwick (2017) suggest that “technology use is central to everything we do” (p.4), through this thesis, I aim to reveal whether by adopting an inclusive approach to citizen science these opportunities are available to the co-researchers and therefore can break through the ‘digital divide’.

2.2.6 – Citizen Science projects and minority groups

The citizen science literature is growing rapidly, and there are many different types of communities engaged in citizen science projects. Yet, there are clear gaps within the literature of under-represented communities. “Participation in citizen science does not reflect the demographics of the US” (Pandya, 2012: p.314). Similarly, in a survey done by West & Pateman (2015), they identified how white men with higher incomes were more likely to participate in citizen science projects than people from a BAME background or of a different gender. Citizen science is claimed to have the potential be ‘for all’

(Silvertown, 2009), yet these examples show how this potential is not currently being fulfilled. This thesis argues that citizen science should acknowledge and adapt to include more communities. Pandya (2012) moves on in their article to discuss how those who have been historically excluded from the scientific discourse i.e. people with disabilities, and those who are classed as ‘less-affluent’ are less likely to engage than others.

Dibner & Pandya (2018) identify how there is very limited data relating to the demographics of citizen science participants. Yet, their literature review suggests, similar to Pandya (2012) and West & Pateman. (2015), “that members of communities historically under-represented in science, [are] people with less formal education, and people of colour” (p.44). These statements suggest a lack of diversity in practice within citizen science participants. Furthermore, Dibner & Pandya (2018) identify that there is nothing to suggest that these groups cannot engage in citizen science projects. Instead, they suggest that “*all* participants need some encouragement or scaffolding to participate in citizen science, regardless of demography or prior experience” (p.45).

Dibner & Pandya’s (2018) review defined diversity through seven categories:

1. “Gender
2. Age
3. Retirees
4. Race/Ethnicity
5. Education
6. Income
7. Previous Participation in a citizen science or relevant project”

(p.163-164)

Whilst these are all important categories to understanding those participating in citizen science, it does ignore the learning-disabled community. There is no explanation for this provided within the book, displaying further invisibility of this community within the citizen science narrative. By understanding how people with learning disabilities participate in citizen science, we can begin to engage the wider community. Whilst looking at this, this thesis also looks at offering some practical advice on how to ‘scaffold’ participation for adults with learning disabilities in order to engage as many people as possible from this ignored community.

2.2.7 – Summary

In this Section I have reviewed the discourse around citizen science, focusing on how the current definitions and principles do not encompass the involvement of people with learning disabilities. The literature I have presented, highlights how the potential of citizen science to be ‘for all’ (Silvertown, 2009) has yet to be fulfilled. By exploring whether it is possible to adapt citizen science principles by introducing an inclusive approach, this thesis explores whether it is possible to break down invisible barriers to participation found within the processes of citizen science and to genuinely and meaningfully include “under-represented communities and places” (UKRI, 2019).

The literature highlights how there are many different motivations for people to become involved in citizen science. Yet, by discussing these motivations generally, citizen science can be accused of ignoring different communities and the reasons why they might engage in citizen science. This thesis argues that, by focusing on the support required by the learning-disabled community, we can contribute to an understanding of their motivations to engage and create future citizen science studies to suit their different motivations.

I have highlighted how the citizen science literature discusses the benefits of engaging for the participants. These benefits are perceived as key motivations for engagement, yet the literature does not highlight the potential knowledge exchange from including previously under-represented communities. Not only would this benefit the participants but has the potential to benefit researchers and the research.

The citizen science literature discusses those who participate in the research as ‘publics’. There is a danger that this generalised term potentially excludes those who identify as outside the ‘norm’. By opening up discussions on the exclusion of these different communities, researchers can begin to adapt their practices to be more inclusive.

My discussions around these topics has highlighted a need to explore further whether and how people with learning disabilities can engage in citizen science. My thesis aims to explore these issues and offer a dialogue for researchers aiming to engage this previously excluded community.

I will now move on to discuss the literature around learning disabilities, one of the communities excluded from the citizen science discourse.

2.3 – Learning Disabilities

Having discussed the citizen science literature and identifying the gaps in provision for people with disabilities, now I will consider the learning disability literature. In this section I will focus on labelling and self-identity, as I identified that these two topics were influential not only within inclusive research, but more specifically for my project. These topics were identified as influential through the literature as they were frequently mentioned by key researchers in the field. Furthermore, the learning-disabled community has a long history with labelling, the negative connotations created by this. I wanted to reflect this within the literature review and identify key points for my practice within the project. By understanding how labelling and identity are discussed in the literature, I sought to plan and frame my research project to directly avoid any barriers created by these terms. Dawson (2018) identifies how science communication research and activities currently views those that aren't engaged as "concerned" and "disengaged sceptics" (p.774), putting the responsibility for disengagement on the people not engaging rather than the science communicators. This has the potential to identify further, negative labels, assigned to the learning-disabled community by default of their lack of engagement with science communication. This has the potential to identify further, negative labels, assigned to the learning-disabled community by default of their lack of engagement with science communication. It is the responsibility of science communicators and those organising citizen science activities to make citizen science more inclusive and engage those currently excluded.

This thesis argues that negative labelling needs to be addressed, if citizen science is to successfully engage currently under-represented communities. Furthermore, this project asked the co-researchers to add a new positive label to their identities, that of citizen scientist. These are key steps in starting to build capacity among excluded communities.

2.3.1 – Labelling

In this section I will look at the concept of labelling and its effect on identity and potential for participation in citizen science. Labelling is the way in which we describe both ourselves and those around us. Becker (1963) defines labelling as the way in which we identify the "deviant" or "outsider" from the social rule's society has in place (p.1). It occurs in day to day life and we often apply labels to people before we have even interacted with them. In Section 2.2.4 of this chapter on citizen science I identified how the label of citizen science or citizen scientist comes with its own challenges. For example, a challenge is being an 'amateur' rather than an 'expert' in the scientific field. This

dichotomy between these terms does not consider the many benefits and the knowledge that citizens can offer science. By changing this language, we can begin to create an equality between the scientific and non-scientific communities.

What is missing from the citizen science literature is an appreciation of how labelling of citizens (and other potential participants) relates to more general societal labels, in this instance to those with learning disabilities. By just using a ‘one size fits all’ label, such as ‘public’, the organisers of citizen science can ignore the different needs of citizens and the different types of capacity that need to be built.

The history of learning disabilities brings to light how the attitudes towards this community have adapted over time. Between the 1800’s and early 1900’s people with a learning disability were labelled as “idiots” (Idiots Act, 1886) and “feeble-minded” (Royal Commission, 1908), which are now seen as negative, offensive and oppressive terms as they focus on the mental capacity of the person. The more recent label of ‘learning disability’ was introduced by the Department of Health in the early 1990’s. It was a response to the wide criticism surrounding the vagueness of the term ‘learning difficulties’ introduced in the mid 1980’s, which could be applied to anyone who struggled with their academic learning (Thomas & Woods, 2003: p.13). However, whilst the label has changed, at least some of the negative connotations have stuck.

Strnadova et al. (2018) discuss how many of their participants (people with learning disabilities), faced barriers to their ‘belonging’. Within this study, the term ‘belonging’ is framed as meaning when people “feel ‘at home’ within their community” (p.1092). The researchers discussed how their participants had faced prejudice, as people “focused on their disability” and would tell them “that there was something wrong with them” (p.1098). The participants of the study also faced barriers from bullying, a common daily occurrence for the majority of the participants. The theme of belonging is widely discussed within the learning disability literature (Frawley & Bigby, 2015; Fenn & Scior, 2019; Abbott & McConkey, 2006; Anderson & Bigby, 2017). These two barriers, where others outside of the learning-disabled community focused on the participants’ disability as a marker of difference, was what stood in their way of ‘belonging’.

This disempowering focus on disability comes more than 30 years after groups such as People First in 1985 argued that people should come before the disability and championed the preferred label of “people with learning difficulties” (Holland, 2011). The social model of disability, introduced by Oliver (1990), furthered the belief that people with learning disabilities are not disabled by their

disability but by the socially constructed barriers (Barnes & Mercer, 1997), such as bullying and prejudice by people without learning disabilities (Strnadova et al., 2018). Whilst there have been many strides in changing the view of the learning-disabled community, society still has a long way to go in helping to remove barriers to 'belonging'.

When thinking about our identity, we often place ourselves within certain labels. These could be labels given to us at birth, e.g. 'black' or 'white' or ones that we gain through the rest of our life e.g. 'single mother' or 'student'. Whilst we may reject some of these, we use these labels to offer others a simple and quick description of who we are, so others can make their judgments on us (Moncrieffe & Eyben, 2013: p.1). However, Beart (2005) identifies how the label of 'learning disability' is not seen as a "salient identity" (p.33) by much of the learning-disabled community. Instead, people within the learning-disabled community may identify better with labels relating to "gender, ethnicity and their personal-tastes" (Hingley-Jones, 2013: p.460). By not identifying with their disability, one might exclude themselves from communities. Beart (2005) identifies how self-advocacy groups were set up to offer safe spaces for people with learning disabilities to advocate for issues relating to them. However, Beart (2005) claims that by not identifying as a person with a learning disability, one cannot "challenge the way they are treated" (p.33). Yet, it could be argued, that those who are part of self-advocacy groups are not rejecting the label of 'learning disabled', instead those not accepting the label are rejecting the way the term is perceived by those outside of their community. Self-advocacy groups are created to allow people to advocate for themselves and their community. This would suggest that Beart's (2005) view that many of the learning-disabled community do not accept the label of learning disability is untrue of those engaged in self-advocacy work.

Whilst there are negative connotations, it is vital to acknowledge the importance of a label, in order to access necessary services (Thomas & Woods, 2003: p.25). These labels provide those within a position to offer services (doctors, nurses and support workers, etc.) the information needed to ensure the correct services are given. The process of labelling has been used to provide necessary help for those who are the subjects, such as the need for additional support and reasonable adjustments at school. Yet, this process also stigmatises those who are labelled and positions them as 'not normal'.

Stigma is defined by Goffman (1963) as a reaction to a stranger who may have different "attributes" (p.12) to what we believe to be socially normal. Goffman describes this reaction as reducing this person "from a whole and usual person to a tainted, discounted one" (p.12). This phrasing identifies the negative and potentially damaging effects that a stigma can have. Earle (2003) highlights how the

typology of the ‘disability’ label and the classification of it “assumes the existence of psychological and physical ‘normality’” (p.3). Yet is there truly a ‘normal’ by which people can be measured? And if there is, the stigma attached to those outside of the ‘norm’ has the potential to be incredibly damaging. The stigmas attached to the label of ‘learning disability’ are vast and, as Richards et al. (2019) highlight, can take the form of “physical and verbal abuse and subtle forms of disempowerment” (p.207). These forms of stigma can threaten people’s ability to engage and can force people to self-exclude based on the stigmas thrust upon them (p.207).

By using these potentially negative labels, science reinforces these barriers instead of actively seeking to challenge it. This thesis aims to explore how these labels could potentially exclude people with learning disabilities from citizen science. My aim is ultimately to add to a more accurate understanding of who can contribute and create a more equitable research community, through the employment of a capacity building programme. I will discuss this further in the next section, by looking at the self-identity and citizenship of people with learning disabilities.

2.3.2 – Self-identity and citizenship

Maalouf (2000) claims that “identity can’t be compartmentalised. You can’t divide it up ... I haven’t got several identities: I’ve got just one” (p.3). Yet, there are many parts of our identity that we shy away from, to project an idealised view of ourselves to the outside world. But what can you do if the part of you that has negative connotations, is what makes you, you? In challenging negative labels and addressing the power differences within research by working *with* participants with learning disabilities (my emphasis), this thesis explores whether it is possible to create a positive space to develop identities as citizen scientists.

As discussed in Section 2.3.1, the label of learning disabilities has had a long history with the current term in use only being put into place in the 1990’s. In recent times, we define children with learning disabilities as being ‘SEND’ (Special Educational Needs and Disability). The government description of SEND is how it affects “a child or young person’s ability to learn”. This allows our educational services to categorise the child or young person and provide the right sort of education and support that the child needs. This label immediately becomes an important part of a child’s identity. As a child grows and adapts to the life around them, they will constantly be reminded of this label, as they’re placed into certain forms of education, specific supported housing and offered benefits for people with disabilities. This, however, is not necessarily a negative. I will now move on to look at how both labelling and identity play a part in a person’s citizenship.

In Section (1.1.1) I mentioned Allgaier's (2010) discussion of a citizen's 'rights' and 'duties' to enact their citizenship. Allgaier describes these as a responsibility to participate in scientific inquiry that affects society. What Allgaier (2010) does here is refer to citizens as one big group. He ignores the different challenges that different communities may face when trying to perform their citizen 'duties'. Morris (2005) mentions this in their discussion of citizenship, specifically for people with learning disabilities in the context of their rights as a citizen.

Morris (2005) introduces three concepts which enable a person with learning disabilities to fulfil their citizenship: self-determination, contribution and participation. The second of these, contribution, highlights the issues with Allgaier's (2010) statement of a citizen's "rights" and "duties". Morris (2005) claims here that the literature and discussions around citizenship focus on these "rights" and "duties" required of a person. However, if a person is regularly segregated and oppressed throughout their life due to a label, they may not be capable of enacting these "rights". This also has the potential to affect both self-determination and participation. At the end of her paper Morris (2005) questioned, "If, in 15 years' time, disabled people really do have "equal opportunities to participate and contribute as equal citizens", this will mean that we have a society where difference does not mean you cannot 'belong', but where instead our common humanity is recognised and valued." (p.40). Now at that 15-year mark, I aim to address this within this thesis, creating opportunities for people with learning disabilities to own a citizen science project as citizen scientists.

2.4 – Inclusive Research

Having considered several of the key barriers faced by the learning-disabled community regarding labelling, identity and their engagement in citizen science, this section will now explore a research approach that has sought to offer a more progressive alternative. As such, this thesis aims to discuss whether this different methodological approach to citizen science offers the types of support necessary to build capacity. I will now look in detail at inclusive research, first offering a brief explanation of what the research approach is, and its history.

In 1981, an organisation called the Disabled People's International formed and, in their first congress speech they declared:

"That all people are of equal value. This conviction implies that disabled people have the right to participate in every sphere of society...Disabled people have the right to equal participation

in the decision-making processes of all political services and programmes that effect their lives.”

(Disabled People’s International, 1981)

This call to action influenced disabled and non-disabled researchers alike to perform their research in ways to seek to create equal partnerships between those with disabilities and those without. It is a combination of a call to action, further informed by exploratory practices that forged the path for inclusive research.

This call to action continues to influence research with people with learning disabilities, inspiring a tradition of involving the community in the research process instead of using them as participants. Inclusive research aims to fulfil this call, by engaging people with learning disabilities as co-researchers instead of participants.

Inclusive research was coined as a term by Walmsley & Johnson in 2003. Its foundations lie in the field of disability studies. Disability studies developed over the years moving from the previous medical model of disability to the social model of disability developed by Oliver (1990). The social model is described by Barnes & Mercer (1997) as reversing “the causal chain to explore how socially constructed barriers have disabled people with a perceived impairment” (p. 1-2). This model of disability highlights the beginning of a change in attitude towards disability, from the belief in a medical model where a person’s disability is a flaw, to the application of a social model where a person with a disability is disabled by the way they are perceived by society instead of their impairment.

Bigby et al. (2014) describe inclusive research as an “umbrella term” referring to the terms ability to allow “for diverse approaches and forms of involvement by people with intellectual disability” (p.4). Within the inclusive research literature, there is much tension around whether inclusive research is truly an umbrella term or whether it is different to participatory and emancipatory research.

Participatory research is described by Cornwall & Jewkes (1996) as being “motivated by pragmatism and concerns of equity” (p.1667). Bourke (2009) identifies the lack of “strict rules” and its “bottom-up” approach, defining it as “a research process which involves those being researched in the decision-making and conduct of the research” (p.458)

Emancipatory research is described by Noel (2016) as a “research perspective of producing knowledge that can be of benefit to disadvantaged people”, she describes it as “seek[ing] to empower the subjects of social inquiry” (p.1-2). Danieli & Woodhams (2005) discuss how the focus of emancipatory research is on the “political outcome” (p.284) whereas Barnes (1992) focuses on the ‘empowerment’ aspect of emancipatory research and how it is “the establishment of a workable dialogue between the research community and disabled people” (p.122) to facilitate this empowerment. Already, there is a tension here between emancipatory and participatory research where within emancipatory research there is a focus not just on the process, like in participatory and inclusive research, but also on the impact of an outcome. Therefore, the question should be raised as to whether the term inclusive research can be used as an umbrella term. Nind (2014) discusses this in their book ‘*What is Inclusive Research?*’, where they suggest that there are other terms that may be a preferable umbrella term such as “collaborative research” (p.5). In this thesis, I refer to inclusive research as a research approach not as an umbrella term. The purpose of this is to concentrate the discourse on the methods used and their inclusivity, avoiding the tension of the use of an umbrella term.

For the purposes of this thesis, I will explore how the principles and practices of inclusive research apply as a research approach for the community selected for this project. Inclusive research offers a reflexive and open approach, which I argue is best suited to working with co-researchers who have different needs and requirements. In the remainder of this section, I will discuss how inclusive research is done, explore whether people with learning disabilities can engage in inclusive research and look at the similarities and differences between this research approach and citizen science.

2.4.1 Principles informing how inclusive research should be done

Inclusive research is a term that is informed by several key principles. Walmsley and Johnson (2003) argue, for example:

- “That research must address issues which really matter to people with learning disabilities, and which ultimately leads to improved lives for them
- That it must access and represent their views and experiences
- That people with learning disabilities need to be treated with respect by the research community”

(p. 16).

These principles guide researchers in essential parts of inclusive research. They show the extent to which any research conducted alongside people with learning disabilities, must involve this community. Notably, this approach is analogous to ideas about upstream and downstream engagement, which is a concept from the public engagement literature, but one that is rarely mentioned in relation to citizen science projects. Upstream engagement refers to participation between experts and non-experts to further relationships and increase knowledge of a research topic during the initial planning process. Downstream engagement is the continuation of this exchange of knowledge throughout the research cycle (Wilsdon & Willis, 2004).

Later in the same book, Walmsley & Johnson (2003) offer more in-depth principles for researchers doing inclusive research:

- “Research problem should be owned (not necessarily initiated) by people with disability
- It should further the interests of people with disability; researchers without disability should be on the side of people with disability
- It should be collaborative, people with learning disability should be involved in the process of doing the research
- People with learning disability should be able to exercise some control over the process and the outcomes
- The research question, process and reports must be accessible to people with learning disabilities.”

(p. 64)

Again, these set out principled guidelines for researchers to consider when (co)designing inclusive research. I argue that they offer more guidance on how to deliver an equitable approach to research than is discussed in the citizen science literature (Section 2.2.4). Walmsley & Johnson (2003) offer more detailed guidance, whilst still allowing for discretion among the participants when planning a study of this kind.

Seale et al. (2014) offer a description highlighting many of the same factors of inclusive research as Walmsley & Johnson’s (2003) first set of principles:

“This is research in which those who tend to be objects of other people’s research become agents in the conduct of research, ensuring that such research addresses issues that are important to them and includes their views and experiences.”

(Seale et al., 2014: p. 347).

This description also highlights a key difference between much of citizen science and inclusive research, that the people with learning disabilities are not just consulted or used as research subjects, but instead offered the opportunity to be in partnership with non-disabled researchers. Medvecky and Leach (2017) identify how, within science communication, there is not an established set of norms of which to follow, therefore the ethical landscape in which science communication sits is, at best, foggy (Ibid). Without a set of guidelines, or practical examples to follow, science communication has yet to fully embrace inclusive participation.

Medvecky and Leach’s call for science communicators to “define the beast” (2017, p.4) opens the opportunity for these guidelines and examples to be developed. This thesis argues that through the use of inclusive approaches to citizen science, and engaging publics as more than just ‘subjects’ the ethical landscape can move from a theoretical possibility into an everyday reality.

Woelders (2015) expands further by offering a more detailed description of inclusive research:

- “Inclusive research involves people with intellectual disabilities actively and strives for empowerment and normalisation
- People with learning disabilities are not just the object of study but are actively involved in the research process as participants
- The voice and experiential knowledge of people with intellectual disabilities enrich the professional perspective and the involvement helps to gain entry and access to the broader community and advocacy organisations.”

(p. 528)

This version of inclusive research offers another layer, that of purpose whilst also valuing the knowledge and experiences of participants. It does this by highlighting how the research itself needs to focus on “striv[ing] for empowerment”.

Moving into the present Nind (2017) offers a brief description of inclusive research as it sits now:

“The concept encapsulates the drive to involve people in the design and conduct of research about them, reach and represent their lived experience, respect them and value different ways of knowing.”

(p. 278).

The principles above highlight a key difference between much of the citizen science literature and inclusive research. There is currently nothing within the literature that precludes citizen science activities being co-designed in accordance with inclusive research principles. Inclusive research has echoes, for example, in the work of public engagement researchers, including Irwin (1995), Irwin & Wynne (1996) and Dawson (2018) as discussed in Section 2.2.1. This identifies that, whilst there will be practical challenges co-designing citizen science activities in an inclusive manner, theories are in place to inform this process, I argue that with commitments the practicalities can and should be overcome.

From these principles we can see the journey that inclusive research has taken. Beginning with disability studies which reacted to the societal move from a medical model of disability to a social model (Barnes & Mercer, 1997; Oliver, 1990). The similarities and differences between participatory and emancipatory research and the tensions and confusion this caused contributed to a call by researchers such as Walmsley and Johnson (2003) for the use of the umbrella term ‘inclusive research’. Nind’s (2017) description of inclusive research focusing on the process and inclusion within research moved the principles on. Finally, inclusive research is continuing to develop with projects such as the focus of this thesis adding to the dialogue. It is important to note, however, that the principles all have focus on the removing barriers in research from an underprivileged and often ignored community. All the principles discuss how to make research more equitable and the reasons why this is a good thing for both the learning disabled and research community. This thesis will look at these principles and whether by applying them to a citizen science project they can support people with learning disabilities in their engagement. Before discussing this, I will discuss inclusive research studies in which people with learning disabilities were engaged and look at their involvement within the project.

2.4.2 People with learning disabilities doing inclusive research

Walmsley & Johnson (2003) discuss in their principles the importance of providing people with learning disabilities the ability “to exercise some control over the process and outcomes” (p.64) of an

inclusive research project. Researchers interpret this in their own way. In this section I will look at different inclusive research studies and the ways in which they involved people with learning disabilities in the process.

One key feature of much of the inclusive research literature, is a focus on the process. Many different inclusive researchers report on their research process and the impacts these have had on their co-researchers (Frankena et al., 2018 (a); Nind & Vinha, 2014; Nind, 2017; Riches et al., 2017) In each of these studies, inclusion takes on a different form. Ellis (2018) discusses how they involved people with learning disabilities in the decision-making process of their research project. For them this meant involving them in making the decisions of “topics to research, methods to be used, dates and places to meet” (2018, p.460). When reflecting on this process, Ellis mentions how it “was complex and, at times, fraught” (2018, p.460). The key argument she makes within this reflection is that in attempting not to be “disempowering” (p.461) with her participants, she did not impose a particular structure on the interactions. Her participants however, found this frustrating, leading them to declare: “just tell us what you want us to do and we’ll do it” (p.461). This highlights an important part of inclusive research, that the people being involved are used to being disempowered. For a researcher, this often means being reflexive to your co-researchers’ needs and addressing the lack of trust by building confidence in research, and the researcher. Ellis also highlights the importance of negotiation within groups to make decisions, again pointing out how “real or perceived power imbalances” (p.461) can negatively impact on this process. This paper discusses the importance of being able to reflect not only on the co-researcher’s roles within an inclusive study, but also the researcher’s role. I highlight this paper as it identifies key issues which relate to my project, the importance of reflecting on the researcher’s role. As I will discuss later in this thesis there were challenges in relinquishing control and creating an environment of equity within our research group. I was only able to understand this through reflecting on the roles within the project.

Nind and Vinha (2014) discuss their study, where they brought together people who do inclusive research to discuss the difficulties of this approach, and the different processes used. The researchers used focus groups to encourage these discussions and employed creative activities to inform the discussion. The different groups involved in this study ranged from academic researchers involved in research with people with learning disabilities, policy makers and people with learning disabilities who engage in research in different roles. By engaging these different groups of people, all of whom are impacted by inclusive research, Nind and Vinha were able to “open up a dialogue” (p.108) regarding

the inclusive research process. This work is generative in inclusive research and identifies how this research approach is still changing.

Another example of a different form of inclusion is the ‘The Veronica Project’ by Tuffrey Wijne & Butler (2010). The study looked at the experiences of 13 people with learning disabilities who had cancer. In this study, the researcher chose to involve one person with learning disabilities in the data analysis section of the project. The researcher, Tuffrey-Wijne, had already completed thematic analysis with a colleague. However, the non-disabled researchers then decided to ask Butler, a researcher with learning disabilities, and others to thematically analyse the data to then “cross-compare” (p.178). Later in Tuffrey-Wijne’s paper, Butler discusses his experience of being involved in the study in this way. He discusses how the process, and the focus on the distressing topic of cancer, “was harrowing at times” (p.180). This points to a key feature of inclusive research. By involving the people who are directly influenced by the subject matter, researchers must be aware of the potential for distress on the co-researchers. Whilst this must be a key consideration for all researchers when conducting any kind of study with people, when involving people directly influenced, the researcher must be aware of the potential to inflict additional damage. Another key part of Butler’s reflection was that “it is important to take time and to make time” (p.180) for your co-researchers to learn new skills and explore new emotions alongside the researcher. This conveys again how as non-disabled researchers; we must be aware of the impacts on learning disabled researchers and be attuned to their needs.

When discussing the recommendations, Tuffrey-Wijne & Butler (2010) highlights the importance of questioning the ‘added value’ involving people with learning disabilities in the analysis process can have (p.180). In the paper, this is discussed in terms of resources and time, yet I argue it is also important to weigh up the ‘added value’ against the potential stress being involved in this part of the research process can have on people not accustomed to it. This highlights the importance of a reflexive approach, whereby researchers constantly evaluate research practice. When we read qualitative data and analyse it, we are being given an insight into people’s thoughts and feelings. These at times can be traumatic and can create negative feelings. Hammersley & Trainaou (2012) identifies how researchers can cause harm to themselves within research “as a result of risks that they have consciously taken, or of decisions they did not recognise as carrying any threat” (p.73). The reading of data, and the related emotional harm this can cause to a researcher is not a risk that is necessarily assumed within research. However, as trained researchers, we have specific support systems within institutions to rely on if this is the case. Furthermore, we have previous work with sensitive topics and literature, from which to

learn. The lead researcher must ensure these are available for others involved in the project. This, I argue, is key in inclusive research. Only by understanding the impact and the importance of the research on both the co-researchers and the non-disabled researchers can we focus on developing a beneficial process.

Inclusive research is conducted in many ways by different researchers. Schwartz et al. (2020) identified the confusing nature of this for researchers so engaged six co-researchers with learning disabilities and eight inclusive researchers in narrative interviews with the aim of understanding “the processes that foster and maintain inclusive research with individuals with learning disabilities” (p.236). Through these interviews the (Schwartz et al., 2020) identified six key themes:

1. “Team members characteristics influence inclusive research collaborations – each group will have a different dynamic and by integrating the different characteristics and expertise of the team members, the group can work out how to collaborate inclusively together.
2. Making inclusive research accessible requires identification of support needs and reacting to these both with research materials and research meetings – similar to the theme above by understanding the needs and experience of the different team members, the research can be structured to adapt to these and ensure it is inclusive in its approach.
3. Inclusive research collaborations are maintained by perceived benefits – the personal and societal benefits of inclusive research, and the discussions and understanding of these are what create fruitful collaborations.
4. The role of relationships – the opportunities to build new relationships and create trust between team members facilitated teamwork and created a supportive environment in which discuss difficult topics.
5. Teams’ processes and structures facilitate inclusive research collaborations – structuring to ‘foster equality and be responsive’ – through adopting inclusive approaches and allowing space for the processes to be adapted and refined, collaboration between all team members.
6. The impact of contextual factors such as time and funding impact on different team members and their aims for the study. For example, if an academic team member is focused on fulfilling their funding requirements this might impact on their collaboration and the extent to which the research is inclusive.”

(p.239-243)

Schwartz et al.'s (2020) study offers suggestions to both researchers and co-researchers who engage in inclusive research, to inform their practice. By involving co-researchers with learning disabilities in the process of understanding the inclusive research approach, previous studies were able to gain more insights as to how to conduct research studies of this kind.

Within the inclusive research literature, researchers not only report on the overall inclusive process, but focus on the methods they employed to achieve inclusivity (Cluley, 2016; Nind & Vinha, 2014b; Ollerton, 2012). Durrel (2016) discusses their journey as a doctoral researcher conducting inclusive research by explaining two methods they employed during their data collection; research advisory group and focus groups. The research advisory group was set up with three aims:

1. "Supporting the engagement of people with learning disabilities in the co-production of knowledge, as active members of research communities and by doing so, members were able to exert some direction over the process and outcomes of the study
2. Involvement in the group's activities could contribute to the emancipatory process of its members
3. Offering ongoing contact with people with learning disabilities and their supporters"

(p.2316-2317)

These aims were key to the success of the group and provided the researcher with the constant contact with people with learning disabilities to inform their practice.

Durrell also used focus groups within their study, which followed the same aims as the research advisory group. The main focus of the focus groups was to discuss "behaviours of oppressors" (p.2317) through the examination of representations within media. Whilst there was structure applied to the meetings, they were open to allow members to "articulate their views "in their own 'language' and on their own terms" (p. 2321).

I have chosen to highlight this study in this section as the two methods outlined here convey very different ways in which people with learning disabilities can be involved in inclusive research. By involving them as 'advisors' the participants with learning disabilities have some control over the study and how it is conducted. Furthermore, it allows the researcher to be held accountable to the community they are researching with. The focus groups described in this study offered members the opportunity to engage in research in their own way and contribute to a narrative regarding a link

between disability studies and media that has not been made in many studies previously (p.2317). By introducing the focus groups in this setting, the co-researchers of this study are potentially opening the discourse up to people with learning disabilities who may not have engaged with it before.

Capacity building has a big role within the inclusive research literature, with many researchers highlighting the importance of learning from each other's skills (Bell & Mortimer, 2013; Embregts et al., 2018; Strnadova et al., 2014; Fullana et al., 2017; Puyalto et al., 2016; Inglis & Cook, 2011, Bigby et al., 2014). Within an inclusive research study, capacity building can take many different forms. For some it may involve research training in order to develop special skills, but more commonly the capacity building is about building the confidence of the co-researchers. The 'Money, Friends and Making Ends Meet' project run by Tilly (2015) worked with a group of adults with learning disabilities to explore their lives and the strategies they use to cope (p.122). The study employed four different data collection methods: focus groups, unstructured and structured interviews, and researchers' observations and reflections. A key takeaway from this study was the importance of the study on the co-researchers lives (p.126). Whilst there was a direct impact through opportunities for dissemination of their findings, the co-researchers also identified how through their involvement in the study they were "enabled [to have] a voice, identify the social barriers in their lives and gave them support and confidence to take action about them" (p.121). Therefore, I highlight this study as this is a key part of any inclusive research approach. Through participation, there are key benefits to be found which can sometimes be just as if not more important than the tangible outputs of the research.

There are many ways to involve people in research, as has been discussed both above and in the citizen science section of this chapter. Involving people with learning disabilities in inclusive research involves a large amount of reflexivity on the non-disabled researcher's part, in order to ensure the research is not disempowering for any person involved.

2.4.3 Summary

The literature identified in Section 2.4 has explored in detail the varied and complex ways in which people with learning disabilities are involved in inclusive research. Firstly, I discussed the focus on the inclusive research process and the impact this has on the co-researchers. The project discussed in this thesis was aimed at providing the co-researchers with a detailed experience of the research process. Furthermore, the co-researchers were given opportunities in which to discuss the impact of the process and self-evaluate their own capacities within this process.

I also discussed the importance of capacity building within the inclusive research literature. This influenced my research in planning time and extra sessions where the co-researchers could build their research capacities. Furthermore, the literature discussed above influenced my role within the group. By allowing myself to be part of the group, rather than actively trying to be a bystander, I created a role for myself where I could provide direction if the co-researchers needed it and also create opportunities for the co-researchers to empower themselves.

Finally, a key influence from the literature discussed above on my research project was the importance of weighing up the ‘added value’ against potential harm of the co-researchers. I approached this issue by creating space and time within the project for the co-researchers to have supportive discussions if personal issues were raised and allowing for conversations to develop outside of the project.

Having discussed the different ways people with learning disabilities are involved in inclusive research, I will now move on to look at the similarities and differences between inclusive research and citizen science.

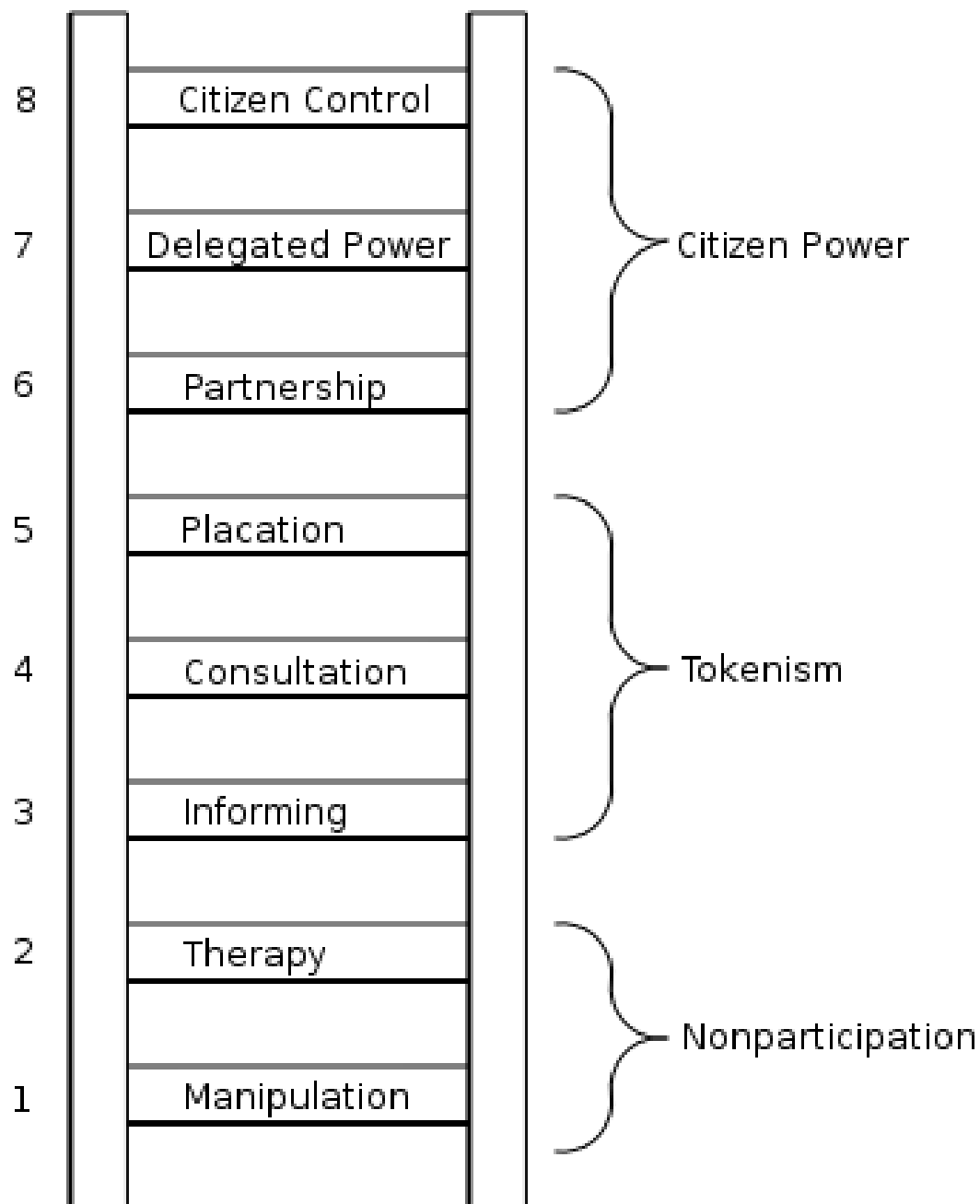
2.5 – Similarities and differences between citizen science and inclusive research

In this section, I will look at Arnstein’s (1969) participation ladder and apply this to both citizen science and inclusive research. In doing so, I will explore some of the key similarities and differences between these two research approaches. Arnstein conceptualised the participation ladder to “encourage a more enlightened discussion” (1969, p.216) about participation in planning processes in the US. Notably, the ladder was conceptualised before the emergence of inclusive research or recent conceptualisations of citizen science. It is applied here because participation plays a key role in both, as inclusive research, and citizen science aim to break down barriers and engage citizens as co-researchers. Arnstein (1969) identified different levels of participation with research, showing this diagrammatically in the form of a ladder (Figure 3).

I argue inclusive research, in its idealistic form, sits within the top section of the ladder (citizen power). It fulfils the criteria of including citizens within the entire process and giving them ownership of the study. This defined approach to participation differs to other forms of participatory research. Citizen science, for example, can take many different forms of participation and could be positioned anywhere on Arnstein’s ladder, depending on the degree of participation on the part of the citizens.

Notably, whilst some theoretical conceptualisations of upstream engagement offer the potential for citizen power to be realised (e.g. Wilsdon and Willis, 2004), much of the literature on practice indicates the citizen science is often situated further down the ladder.

Figure 3 - Arnstein's ladder of participation (1969)



When discussing some of the key criticisms of citizen science, Higgins (2015) highlights that if an expert scientist were to engage in scientific inquiry and publish a paper about it, the scientist gains a citation. Citizen scientists, however, “transform into that footnote under the conclusion thanking ‘everyone else’ who contributed to the project” (p.1), making their contribution to the project seem less than that of the researcher. This identifies a lack of inclusion in the research team and diminishes the citizen scientist’s importance within the research.

Haklay (2013) suggests four different levels of participation in citizen science:

1. “Crowdsourcing – Citizens as sensors, volunteered computing
2. Distributed Intelligence – Citizens as basic interpreters, volunteered thinking
3. Participatory Science – Participation in problem definition and data collection
4. Extreme Citizen Science – Collaborative science: problem definition, data collection and analysis”

(p. 116)

If we are to follow Haklay’s typology of participation, then the project discussed in this thesis could be described as “extreme citizen science”, because of the collaborative approach it takes. Haklay argues that “extreme citizen science” is the collaboration of “professional and non-professional scientists” in citizen science projects from the decision of issues to the “analysis and publication or utilization of results” (p.117). This typology is the closest to the project discussed in this thesis within the citizen science literature. Yet, within Haklay’s description, there is still no acknowledgement of the ‘expert’ status of the ‘non-professional scientist’. Furthermore, it still assumes a level of knowledge of research skills and therefore potentially excludes those without it. Whilst ‘extreme citizen science’ certainly progresses the field, it still ignores the under-represented communities and therefore this thesis questions whether it is ‘extreme’ enough.

Furthermore, the question must be asked, where is citizen science positioned when engaging people with learning disabilities? Is capacity building required to ensure that engagement moves from a potentially disempowering ‘tokenism’ level of participation to ‘citizen power’? This thesis explores whether (and how) it is possible to answer these questions.

One key difference between citizen science and inclusive research, is a focus on inclusivity for people with learning disabilities. Irwin (1995) claims that “citizens are impoverished by their exclusion”

(p.26) from science. During my review of the citizen science literature I have not found a citizen science project that specifically aims to tackle issues of exclusion for people with learning disabilities. People with learning disabilities are routinely excluded from citizen science.

Inclusive research offers the opportunity to engage people with learning disabilities in citizen science by exploring capacity needs. In the next section I will discuss the literature surrounding research skills capacity building for people with learning disabilities and look at how this connects both citizen science and inclusive research.

2.6 Capacity building

In this thesis I aim to explore whether capacity building can support people with learning disabilities to participate in citizen science by offering a safe environment for co-researchers to discover their potential and learn new skills.

Nind et al. (2015) identify an assumption within the discourse of capacity building that people have “at least a fundamental grounding in research skills” (p.543). Yet, this isn’t the case if the people involved have never had experience of research. A key importance in the capacity building of people with learning disabilities is that through the training they do not lose their “valuable insider” perspective (p.550). Nind et al. (2015) argue that conversations regarding capacity building for people with learning disabilities need to be had.

Inglis and Cook (2011) facilitated a study in which they engaged men with learning disabilities and their related staff members in a collaborative research study. Here, the co-researchers were engaged in all parts of the study. In preparation for the study, they engaged the co-researchers in drama-based workshops to promote discussions and “engage in learning and knowledge building” (p.99). Furthermore, these workshops engaged the co-researchers in “developing understandings and finding the confidence to articulate and critique thoughts and ideas” (p.99). Inglis and Cook highlighted how these workshops were key to the co-researchers’ understanding of research and were the place “where a recursive process was utilised” (p.100). After the study was completed, the researchers and co-researchers created “ten top tips for effectively engaging people with learning disabilities in research” (p.101). The first of these highlights that when conducting research with people with learning disabilities, “there should be a presumption of capacity” (p.101). Furthermore, the final tip highlights the importance of a “collaborative recursive process” (p.103) in the co-researchers learning process. This identifies that when capacity building with people with learning disabilities, the researcher must

create a collaborative environment whereby skills and experiences are practiced and explored. My argument is that by adopting an inclusive approach, similar to the one discussed by Inglis and Cook (2011), in citizen science and constantly readdressing our techniques of engagement, more co-researchers may be encouraged to engage with the process and build a larger community of citizen scientists.

In the study by Inglis and Cook (2011), this reflexive approach consisted of offering different formats to enable the participants to engage. Whilst this worked for this study, there are many different formats used in capacity building with people with learning disabilities. This highlights again, the lack of a reflexive pedagogical framework and the default assumption that research skills are largely learnt through trial and error. With many different approaches being employed it is hard for researchers to gain an understanding of what is the right approach to use for the communities being engaged. Trial and error, whilst effective in some contexts can demotivate citizens from engaging when failure is repeated. For example, if learning through trial and error, a citizen scientist may give up their attempts as they find another interest which is less challenging. Furthermore, it could be argued that when working with people with learning disabilities, this could lead to potential non-engagement of one or more of the participants as they find yet another thing that they are excluded from due to their disability.

Bigby et al. (2014) identify that working cooperatively on a project with people with learning disabilities involved combining each person's "different types of knowledge and skills", stating that this was better than "wasting resources teaching skills that duplicate or mimic those of academics" (p.62). By facilitating research skills training, are we ignoring the different forms of capacity that the participants already have?

In this thesis, I aim to answer this question by approaching capacity building in a reflexive and inclusive manner, allowing the co-researchers the opportunity to show the capacities they already have. However, if research is to be truly inclusive and reduce the barriers of the 'expert' and other forms of expertise and experience, then a research process should aim to be inclusive to all. Capacity building enables this. It is also important to note that while Bigby et al. (2014) identify that the group were made up of people who were "different but equal" (p.61), the researchers don't discuss how the group overcame the boundaries put in place by not being able to fully participate in the study due to capacity needs.

Strnadova et al. (2014) highlight these points I have made in the previous paragraph. When working with people with learning disabilities, the researchers introduced a research skills training section, reporting that “research training is an important component of involving people with intellectual disabilities in research in the capacity of researcher” (p.20). Whilst this may not apply to all inclusive studies, it does highlight how ignoring the capacity differences between the participants and the researchers, there is a chance of further disempowering the community. By identifying capacity needs for people with learning disabilities within citizen science, my research aims to contribute to the removal of disempowerment and provide this community with autonomy over their role in citizen science.

2.7 – Summary

In this chapter I have discussed the literature around; citizen science, learning disabilities, inclusive research and capacity building.

The citizen science literature has a distinct lack of discussion about specific communities’ engagement, and how or why certain communities are excluded. In this chapter I asked the question: does the term ‘the public’ do justice to all citizens and can everyone genuinely participate as a result? The literature discusses different exclusion criteria for ‘the public’ who engage. Scientific literacy, whilst important to citizen science, can add another dimension of exclusion. Approaches to citizen science that are based on scientific literacy can exclude communities who may have had negative experiences with science, or who may feel they lack this background knowledge. To address this, this research employs a capacity building approach, whereby the people engaging are given a safe environment to gain confidence, further develop their scientific literacy and increase their science capital. This is where my project sits, identifying how to engage a community who may typically be excluded and offering a different, more creative approach to capacity building.

The learning disabilities literature identified in this chapter focused on the importance of labelling of identity within this community. Morris (2005) questioned whether people with learning disabilities would be treated as equal citizens with the opportunity to participate and contribute to decision making. Citizen science, whilst having exclusions, was claimed by Silvertown (2009) to be a potential tool for participation “for all”. By linking these two ideals, this thesis argues that citizen science can be used to create practical opportunities for the learning-disabled community to participate, offering a more equitable form of public engagement.

The third topic of focus in this literature review was inclusive research. This thesis identified how the principles of inclusive research focus on the process. Citizen science on the other hand, had fewer explicitly stated principles and whilst discussing the process also had a focus on the output of the research. By applying the principles of inclusive research to citizen science, this thesis argues that researchers can create a more equitable and inclusive form of public engagement.

Finally, this literature review looked at the capacity building literature. This thesis posed the questions: by facilitating research skills training, are we ignoring the different forms of capacity that the participants already have? By using an inclusive approach to capacity building, this project will build on the different types of capacity held by the co-researchers whilst still creating a space to develop new research skills. Focusing on learning disabilities, the literature identified the need for measures for capacity building for this community. By using both an inclusive approach and the citizen science research process as a tool for engagement, this project aims to open the discussion of these measures.

The many different topics discussed above all impact on my project. By highlighting the lack of knowledge in many of the topics, around the learning-disabled community, I aim to begin the creation of a knowledge base through this thesis.

Having discussed the literature around the key topics of this thesis, I will now move on to look at the methodological basis of this project.

Part Two – ‘Nothing about us without us’: Inclusive Research Design

Chapter 3: Methodology

3.1 Introduction

The aim of this project is to co-design a capacity building programme that: introduces adults with learning disabilities to citizen science; offers a safe space for their development of trust, rapport and mutual understanding between co-researchers; and supports co-researchers to both develop their capacity to engage in citizen science and undertake their own citizen science project.

The project was conducted in partnership with the Oxfordshire self-advocacy charity, My Life My Choice, specifically, their Banbury based self-advocacy group. The process and experience of engaging in this programme is evaluated in order to address the research questions outlined in Section 1.1.3.

In this chapter I will first outline the philosophies that underpin the design of the programme. I will then move on to provide a justification for the methods used to collect data emanating from the implementation of the citizen science project. Next, I will discuss the context in which the research was conducted in, discussing the design, describing the co-researchers and the setting in which a structured programme was implemented. I will then discuss the methods employed to analyse the data. Finally, I will outline key aspects of the project design in relation to reliability, validity and ethics. In Chapter 4 I then outline the different phases and activities of this programme.

3.2 Methodological Position

3.2.1 Epistemology and Ontology

Epistemology is described by Cohen et al. (2000) as concerning “the very bases of knowledge – its natures and forms, how it can be acquired, and how communicated to other human beings” (p.6). Prior to, and whilst conducting a research study, a researcher will form their opinion on how to gain the knowledge needed for the research. This, in turn, impacts their practice as a research facilitator and influences their choice of research methods.

In 1962, Schutz argued for the creation of a new and distinct science to study the social (Potter, 2002: p.78) as, “nature as explored by the natural scientist does not ‘mean’ anything to molecules, atoms and electrons... [but has] specific meaning and relevance structure for the beings living, acting and thinking within it” (Schutz, 1962: p.59). Social constructivism as an epistemology, builds on Schutz’s ideas suggesting that “most of the knowing that is done is concerned with trying to make sense of what it is to be human, as opposed to scientific knowledge” (Andrews, 2012). Inclusive research reflects

these ideas, focusing on ‘what it is to be’ a person with a learning disability in particular investigating the differing ways knowledge is produced in these societies.

Earlier in this thesis (Chapter 2.4) I discuss how this research aimed to move away from the “medical model” of disability to a “social model” (Oliver, 1990; Barnes & Mercer, 1997). This meant focusing on the social causes of disability, as opposed to the medical, and using the research to overcome these. Nowotny et al. (2003), discuss “Mode 2” knowledge production which is “socially distributed, application-oriented, trans-disciplinary, and subject to multiple accountabilities” (p.179). This form of knowledge production follows five characteristics, which I will describe below relating them to this research:

1. **“Context of application”** – The inclusive research methods used in this study, focus on working *with* the community and providing opportunities to build capacity and produce knowledge together.
2. **“Trans-disciplinarity”** – This research study uses different qualitative research methods (Chapter 3.3) to allow for an adaptive research approach.
3. **“Diversity of sites at which knowledge is produced, and the types of knowledge produced”** – This study was conducted alongside an already established self-advocacy group (Chapter 3.4.2) working at their locality as equitable partners in research. This impacted the type of knowledge produced, allowing for reflection on researcher practice and co-researcher capacity (Chapters 5&6).
4. **“Reflexivity”** – A key focus of this research was the reflexive approach on the part of the researcher. Identifying how the responsibility for facilitating and ensuring engagement lies with the scientists, not the potential participants.
5. **“Partnerships”** – This study was based around the idea of equitable partnerships through the use of inclusive approaches, to create opportunities for new types of knowledge to be produced.

(p.186-187)

This thesis focuses on the importance of equitable research, to create knowledge which has a wide-reaching impact. The epistemological approach discussed by Nowotny et al. (2003) of “Mode 2” knowledge production, supports this and provides a theoretical basis on which to produce new and important knowledge.

An ontological belief focuses on “the very nature or essence of the social phenomena being investigated” (Cohen et al. 2000, p.5). In this thesis, the “social phenomena” investigated is the

exclusion of people with learning disabilities from the citizen science narrative, through the lens of capacity building. To conduct this investigation, the study had to explore both the ‘social’ and ‘independent’ exclusions placed on this community. Latour (2003) discusses how the phrase ‘social’, in relation to a social constructivist ontology, denotes two meanings. Firstly, “the stuff out of which things of science are made”, and “the harder structure that explains the long-term solidity of scientific facades” (p.4). Whilst Latour is using these meanings to identify the “implausible role for the social” (p.2) for constructivist ontologies, this thesis identifies how the social aspects, and indeed the distinct groups that people are labelled in a particular way (Chapter 2.3.1), impact their exclusion and therefore capacity to engage with certain social phenomena. By focusing on the processes and capacity building of the study (i.e., the social), and less on the issues being research and the products of citizen science (i.e. the construct), this study sought to empower the co-researchers through supported social processes to explore constructs which have social and personal meaning to them in the future.

In Section 3.2.2, I will discuss the positivist underpinnings of citizen science. Whilst this study takes a different approach, highlighting the importance of the social over the scientific method, it is as equally valuable. I will now move on to discuss the research paradigm used within this study, critical research.

3.2.2 Research Paradigm

My research focuses on readdressing power differences within research and improving the visibility of the learning-disabled community. This corresponds with the aims of critical research which aims “to realize a society that is based on [equity] and democracy for all its members” (Cohen, Manion and Morrison, 2000: p.28). I am therefore positioning the project reported in this thesis as being within the critical research paradigm, specifically using inclusive research methods (see Chapter 1, Figure 2).

Why have I chosen to situate this research within a critical research paradigm? This project aims to break down barriers between citizen science and the learning-disabled community, to ensure citizen science processes respect and include the learning-disabled community and their voices.

Critical research, whilst aiming for equity, also identifies the issues in “consciousness that has brought an individual or social group to relative powerlessness” (Cohen, Manion and Morrison, 2000: p.37). Cohen et al. (2003) also draw a link between participatory research (Chapter 2.2) and critical theory explaining how participatory research is “an instance of critical theory” (p.37).

Clough and Nutbrown (2007) identify critical research as having an emancipatory interest (Chapter 2.4), involving participant researchers to investigate “the taken for granted” (p.17). This is a clear link

to inclusive research which looks at issues affecting the learning-disabled community, focusing on engaging the community as active members of the research rather than passive participants.

Daley (2010) highlights how a critical feminist approach “promotes the use of researchers’ reflexivity and critical reflection to recognise and respond to power structures and relations in the research process” (p.68). This highlights a key part of the critical research paradigm in general, that it is aimed at both “recognising and responding” to the inequalities that are embedded within the traditional research process. Boyask & Vigurs (2018) discuss the issues faced by researchers who are doing critical research specifically how by highlighting the “critiques of social status quo and its oppressive inequalities do not sit comfortably with neo-liberal state agendas” (p.218). Again, by challenging the inequalities within research processes and in society more generally, critical research is by its nature unapologetically disruptive. By pushing this inclusive agenda within research, the critical research paradigm seeks to promote equity and impact on disenfranchised communities in a way that research has previously not been capable of doing.

Citizen science on the other hand relies largely on positivist underpinnings. For example, Mueller et al. (2011) emphasise the links to a top-down approach found within citizen science and how this classifies it as following a positivist ideology. The ‘Zooniverse’ platform is an example of this top-down approach where ‘volunteers’ are engaged in scientific research to “assist professional researchers” in their studies (Zooniverse, n.d). Furthermore, Tauginene et al. (2020) identify how citizen science largely uses “positivistic methods of data collection and analysis” (p.2). In a UK context positivism is often characterised by its links to the natural sciences, although it is important to note that positivists apply ‘scientific’ methods to all academic fields. Akin to the ‘engineering model’, positivism seeks to replace theories and ideas surrounding beliefs and practices based on myths, superstitions and customs, with theories and ideas based on evidence discovered through scientific inquiry (Hammersley, 2016: p.18).

One of the key features of positivism is the use of pre-defined procedures with the aim of producing valid, reliable and reproducible knowledge. This links to the reliability of knowledge and the methods applied to produce it. Positivists argue that this approach can help to eliminate the bias discussed in the ‘engineering model’ on behalf of the researcher, meaning the findings are more reliable.

Whilst citizen science is a key part of this PhD research, the positivist underpinnings of citizen science do not reflect the principles of inclusive research. Therefore, a critical research paradigm has been applied to citizen science using inclusive research as the methods in which to do this. This is to allow

for a more reflexive approach which does not rely on ‘pre-defined procedures’ but instead is focused on challenging inequalities within research.

Whilst my research project does not critique the “social status quo” (Boyask et al., 2018) specifically, it is aimed at breaking down barriers between the ‘research expert’ and the ‘other forms of expertise’. Critical research therefore has an influence on my practice in this project by requiring me to reflect on power differences. By involving an ‘under-represented’ community in the citizen science discourse, this project readdresses the power differences within research processes.

Freire’s (1970) *‘Pedagogy of the Oppressed’* is a foundation for critical pedagogy, an influence on critical theory and, as Cohen et al. (2000) argue, inclusive research. Freire’s (1970) three dimensions for research of “listening, reflecting and engaging” (p.103) influence inclusive research and the design of studies such as Nind and Vinha (2014). Each of these dimensions in turn focus on the key principle of inclusive research – collaboration. The first dimension, listening, is described as “engaging with a range of researcher voices” (p.103). This acknowledges the fact that people come to research with different experiences. When used in the context of inclusive research, it focuses on the fact that everyone in the group treated as a researcher has different strengths, each equally weighted. The second dimension, reflecting, is described as “thinking together about those different voices and view” (p.103). Again, this focuses on the idea of ‘togetherness’ that everyone in the room works together to reflect on their different experiences and opinions. This in turn creates a cohesive working environment and can, it could be argued, produce an opportunity for richer data. The third and final dimension, transforming, is described as “learning from and with each other” (p.103). This highlights the idea that whilst people have different strengths, no-one person has more to give than other. It challenges the idea of ‘expert’ and ‘non-expert’, instead emphasising the idea that each person has something to teach another.

The group environment does have downsides, however. When working together, there is a chance for individual voices to be lost to group dynamics. Furthermore, some voices may appear louder than others, and therefore have more of an impact on the data. In this project, I countered this by employing individual interviews to ensure that each person within the project had their voices heard.

This is a practice-based thesis, focusing on the process over the product. Friere’s (1970) *‘Pedagogy of the Oppressed’* highlights the importance of praxis when researching through the dimension of “engaging” (p.103). The practice in this study focused on highlighting the innate issues of power within research, and the importance of creating an equitable research environment. In the next section

of this chapter I will discuss the methods used and the theories behind them. In Chapter 4 of this thesis, I will elaborate on these offering a more in-depth description on the practice-based elements of this study.

3.3 Methods

In this section I outline and justify why the data collection methods used were qualitative in nature, reflecting both traditional and more creative qualitative methods.

Nind (2014) highlights how inclusive research reflects qualitative research aims by “grounding the research in the experiences and views of the respondents” (p.4). Many inclusive studies have focused on giving voice to people within the learning-disabled community, in particular highlighting their experiences and telling stories (Yacoub & Hall, 2006; Strnadova et al., 2016; Tuffrey-Wijne & Butler, 2010; Tilly, 2015; Frawley & Bigby, 2015; Ellis, 2018; Cluely, 2016). Furthermore, as the co-researchers in inclusive research have learning disabilities, more creative and flexible methods have been developed to offer them opportunities to contribute through different forms of communication and media.

Within this project, I used a mixture of traditional and creative qualitative research methods in order to offer both the flexibility of creative methods for different abilities and needs, and also (where possible) to create a space in which to reflect on the creative methods in useful discussions allowing the co-researchers to speak in their own voices. Kara (2015) describes creativity in research as “using transformative research frameworks that are flexible enough to take account of relevant contextual factors” (p.9). It offers a more flexible approach to research, where the researcher can be reflexive to the co-researcher’s needs.

Within the group of co-researchers, there were a range of disabilities. This created different needs. In providing several options for both the traditional and creative research methods, there were opportunities for everyone to have a voice. However, within this group of co-researchers, everyone had different needs and strengths regarding their communication. By combining both sets of research methods, each co-researcher was able to contribute, and a rich data set reflective of the co-researchers’ needs was created. It is important to note however, that the combination of methods is not straightforward and does create more work for the researcher engaging in collating and analysing the data. Whilst this can be seen as a negative, I argue that the positives of a more holistic and rich data set outweigh the time and extra work needed for collation.

3.3.1 Creative methods

Creativity is described by Reilly (2017), when discussing their teaching of graduate research methods, as encouraging “motivation, innovation and problem solving” (p.26). It allows for an alternative way of engaging with previously marginalised groups and vulnerable communities (Jellema et al. 2019), offering a shift from verbal communication-based activities to reflect different competencies and skills. In their book on creative research methods, Kara (2015) discusses how there are differing forms of creativity within research, “Sometimes this will be fluid creativity...sometimes it will be crystallised creativity...sometimes it will be mature creativity...and sometimes it will be eminent creativity” (p.14). Each of these forms of creativity, Kara (2015) claims, are found within all research. In this section I use what Kara defines as “one of the defining features of creativity within research” (p.14) that the creative aspects of this project sit just outside of the ‘norm’ or what may be considered ‘traditional’ within research.

Reilly (2017) claims that “creativity requires individuals to possess a deep knowledge of their own discipline, before attempting to improve it” (p.22). I argue that Reilly’s statement is incomplete, because creative research methods encourage participants to create and discover new knowledge in a safe environment whilst having an impact on the chosen discipline.

A concern that Gillies and Robinson (2012) identified when using creative methods in their study with “challenging pupils” (students who showed what Gillies and Robinson describe as ‘problematic behaviours’ (p.162)), was in relation to the levels of engagement the participants had with the research. The researchers claimed that they had to prioritise the need to generate rapport with the participants over gathering data. I tackled this issue within my project, by going to sessions of the participant group prior to beginning my project with them. This made me less of an outsider and allowed me to build rapport with the co-researchers. Furthermore, I introduced one creative method into the introductory session. This gave me the opportunity to see how the co-researchers interacted with this form of research and reflect this in future sessions. Had this have been unsuccessful, I would have had to check and revise the plan to use creative methods.

In the inclusive research literature, there is discussion about methods (Nind & Vinha, 2014; Strnadova et al., 2016; Walmsley & Johnson, 2003; Seale et al., 2014). Most of the studies discussed within the literature follow traditional methods, such as interviews and focus groups, often with creative adaptations to suit the co-researchers. Within the literature, however, there are examples of creative

research methods being applied in inclusive research. Ollerton (2012) explain how they used the following methods within their inclusive research study; role play and poetry for capacity building, photography and metaphors for examination, photovoice for data collection, analysis and dissemination (derived from Booth & Booth, 2003), and colour coding patchwork as a form of evaluation (p.2). These methods are framed as “creative and accessible tools” which “enhance[d] contribution and opportunities for these co-researchers” (p.1).

Another study that discusses different creative methods was conducted by Kennedy & Brewer (2014). They discuss how the co-researchers were given the opportunity to choose their data collection method, with no fixed research question. From this open brief, the co-researchers chose to improvise and record music, make a scrapbook and take photographs alongside a narrative of these (p.36-37). From these the non-disabled researcher was able to engage the co-researchers in engaging in communicating about their lives. These two examples show the many ways of using creative research methods with people with learning disabilities.

Creative methods used in this project

The first creative method applied in this project was based on the ‘Collage Yourself’ activity found in the ‘Creative Academic’ magazine (Sinfield, 2018). Here the research method is used as a form of introduction to the group for the co-researchers by “making a collage that captured their feelings” (p.8). Brighton University describe collaging to “develop communication skills, encourage reflection on experience, professional and personal development planning” (Brighton University, 2018). Within this project, like Sinfield (2018), collaging was used to introduce the co-researchers to creative methods. Furthermore, it was used to introduce the co-researchers to research and encourage them to think independently about it.

Within the literature, there is debate around how to define a citizen scientist (Chapter 2). In this project, I felt it was important for the co-researchers to identify what a citizen scientist is to them in order to create a shared understanding of this key term. To do this, I adapted Chambers ‘Draw-A-Scientist’ activity (1983). This activity was developed by Chambers to explore stereotypes of scientists. The activity is based on a simple instruction: Draw a scientist. I adapted this activity to explore how co-researchers understood the concept of a citizen scientist. It was designed to encourage co-researchers to consider how they relate to scientists and what their role within science can be. My adapted activity was based on a simple instruction: Draw a citizen scientist.

Another one of the creative methods I apply in this project was developed by Brown (2016) who was researching with people with fibromyalgia. Her ‘identity boxes’ were created as a form of narrative account to help her participants to represent who they were in relation to this condition. Brown describes this method as “an expressive and artistic experience that allows for communication beyond words”, which is why I believe it suited the multiple levels of communication within the co-researchers of this project. In this project, I adapted this method to address my research questions. Within their identity boxes, the co-researchers represented their identity as a citizen highlighting key parts of their identity.

Prior to beginning the project, I piloted some of the creative research methods with Open University PhD students. This was in order to practice my delivery and identify any potential issues with the methods.

The use of creative research methods enabled me to gain insight into the effectiveness of these capacity building methods. Furthermore, these methods offered the co-researchers the opportunity to record their own thoughts and feelings for reflection to make their experience more tailored to them.

3.3.2 Qualitative data collection methods

I used a selection of ‘traditional’ qualitative data collection methods. Largely, I focused on the use of observations to capture data within the sessions that could not be audio recorded. Hammersley & Atkinson (2019) discuss how some ethnographers choose to avoid the use of electronic devices due to their potentially “disruptive” nature (p.154). In this project, I chose to use an audio recorder as I believed the use of audio over audio-visual (i.e. video recorder) would provide little disruption and support the observations in a useful way. I also used both focus groups and one-to-one discussions to allow the co-researchers the opportunity to not only discuss their research, but also to discuss and further explain any artefacts made during the session. The term one-to-one discussions are distinct in this context from interviews, as the method is informal in nature allowing the co-researchers an open space to have conversations about the work. The discussions were unstructured in nature and had a conversational style as opposed to a formal interview style. The combination of these qualitative data collection methods complemented the creative methods discussed above by allowing participants to explain their thinking and share deeper insights. However, it is important to note, that due to the constrictions put in place by the Covid-19 pandemic, semi-structured interviews were used in Phase 3 of the study (Chapter 4). These were used to offer an opportunity of closure of the study, and they

were identified as the most technologically accessible method for many of the co-researchers. I will discuss these qualitative methods in more detail below.

Focus groups are cited within the inclusive research literature as beneficial when working with people with learning disabilities. Cambridge and McCarthy (2010) explain the benefits of using focus groups in this context:

1. “Help people to gain confidence in a group environment.
2. Create safe, non-threatening and non-intimidating environments for user organisation and discussion.
3. Provide for inter-member reinforcement, peer support and validation of views and experiences.
4. Enable members to participate in research from which they would otherwise be excluded due to poor literacy skills.”

(p.477)

These four benefits and opportunities described by Cambridge and McCarthy (2010) are specific to people with learning disabilities and outline the main reasons as to why I used this method to support the creative research methods outlined above. Nind (2008) highlights how focus groups provide a ‘group dynamic’ which helps to build a safe space in which people with learning disabilities can “contribute to research discussions” (p.11). Barr et al. (2003) discussed how in their study on people with learning disabilities views on accommodation, they conducted focus groups in familiar settings. Furthermore, by working with the gatekeepers to this community the researchers were able to recruit 45 participants, more than would have been possible using other methods.

Barr et al.’s (2003) study highlights the importance of conducting focus groups in safe spaces. By employing this tactic within my project and working with the session worker from My Life My Choice (known hereafter as P11), I was able to create a space in which the co-researchers could discuss their opinions in ‘their space’ and on ‘their terms’. Furthermore, by meeting with the session worker from My Life My Choice and discussing research design in advance to the study, I was able to gain rapport with them, making it easier to gain rapport with the group.

Furthermore, I used one-to-one interviews within my project. Hammersley & Atkinson (2007) identify how, “interviews can lead us to see things differently in observation” (p.103). Nind (2008) highlights

how interviews are “at the very heart of qualitative research” and that this method is the way in which researchers “elicit people’s views and perspectives on the world” (p.10). Booth & Booth (1996) identified in their study with “inarticulate subjects” that the barriers of interviewing with people with learning disabilities lie not with the participants, but with “the limitations of our methods” (p.67). The researchers identified four barriers within their study:

1. “Inarticulateness – ‘inability to communicate fluently in words’
2. Unresponsiveness – ‘a limited ability to answer some types of question’
3. Difficulties in generalising from experience and thinking in abstract terms
4. Problems with time – ‘difficulties with dates and numbers’”

(p.56-57)

When framing these barriers as issues with the interviewing techniques rather than the participants themselves, these can be overcome and can include the learning-disabled community effectively in these qualitative research techniques. In this project I addressed each of these barriers individually.

1. Inarticulateness – by using verbal communication alongside creative activities, the co-researchers were offered two different ways of communicating their meaning.
2. Unresponsiveness – by doing interviews one-to-one and adapting the questions for each co-researcher, I could ensure they were able to articulate which questions they could or could not answer.
3. Difficulties in generalising – the whole project was designed to avoid generalisation for the co-researchers, and instead focus on them as individuals.
4. Problems with time – support from the My Life My Choice support worker, who had worked with the group for ten years, meant that the co-researchers could turn to them if they needed clarification with dates and numbers.

A key part in addressing these challenges was being flexible in my approach and allowing the co-researchers to guide the project. By introducing an inclusive approach, the co-researchers were able to guide my practice, instead of me trying to force my way of working upon them. This either eliminated or lessened the barriers described above.

In the project, one-to-one interviews were used in two different ways. Firstly, interviews were employed to validate and support the creative methods. These offered the co-researchers the

opportunity to verbally communicate their meaning and ask for support needed. Secondly, the interviews were used at the end of the project in place of other creative research methods after the Covid-19 pandemic forced the research to be altered. I will discuss this in more detail in Chapter 4.

Finally, I used ethnographically informed observation during the sessions. Ethnography is described by Hammersley & Atkinson (2007) as “involv[ing] the researcher participating, overtly or covertly, in people’s daily lives” (p.3). In this project, ethnography informed the observation as I, the researcher, ‘overtly’ participated in the co-researchers’ regular routine of the self-advocacy group and took notes on their actions and opinions throughout this time. Hammersley (2007) argues that the “naturally occurring” and “unsolicited oral accounts” documented during observation can provide the researcher with a source of “both direct information about the setting and of evidence about the perspectives, concerns and discursive practices of the people who produce them” (p.99). This source of information provides the ethnographers with a deeper insight into the social phenomena they are studying through the views and perspectives of the people affected by it. In this project, the data collected was not ‘naturally occurring’ or ‘unsolicited’, instead the sessions were planned, and the co-researchers were aware of what was happening during each session. The data collected through observation, however, was still rich and the co-researchers spoke freely within the structures of the sessions.

In this project, I used many different research methods to collect data. Whilst this is not common practice within either the citizen science or inclusive research methods literature, it allowed me to capture many different perspectives. Whilst collating all the data did create challenges, it produced a more comprehensive view of the data overall. Having discussed the different research methods used, I will now move on to discuss the context in which the research took place.

3.4 Research Context

3.4.1 Research design

The project was designed in three phases (Table 1). The project was planned this way in order to structure the process and give the My Life My Choice co-researchers an understanding of where the project was going. Furthermore, within the planning process P11 (the session worker from My Life My Choice) had input into early iterations of the research design. They gave their opinions on the structure, timings and exercises planned and shared their knowledge of the co-researchers, specifically how they felt the co-researchers would engage with each session. This gave me the chance to validate the initial design with those who had more experience working alongside the co-researchers. The

design was deliberately flexible, offering alternative options and opportunities to revise design, to allow the co-researchers their input into the project.

Phase one focused on building capacity for the participants to engage in a citizen science project. Phase two focused on enabling the participants to plan and conduct their own citizen science project. These two phases are informed by principles of inclusive research in that creative methods were used to enable participants to fully participate and participants were able to control all aspects of the project. In Chapter 4 I will give a more detailed account of the sessions and activities that took place in all phases.

In the following Sections I provide an overview, with justification, of the creative and traditional methods used to enable participants to fully engage in Phases 1, 2 and 3, and of the qualitative methods used to evaluate them.

Table 2 - Outline of Phases

Role of researcher	Phase of Capacity Building Programme	Methods
Co-researcher	Phase 1: Building Capacity for participants to engage in a citizen science project What is research? Identities as researchers/citizen scientists How to do research	Creative: using creative methods to enable participants to participate Inclusive: pace, content and timing of sessions in control of participants
	Phase 2: Participants plan and conducting their own citizen science project Introducing Citizen Science tools Choosing a topic of inquiry Planning what data to collect and how to collect it Collecting data Analysing and reporting data	Creative: using creative methods to enable participants to participate Inclusive: participants make decisions about all aspects of the citizen science project. Pace, content and timing of sessions in control of participants
Co-researcher	Phase 3: Researcher evaluates the success of the citizen science project	Qualitative: Interviews

One of the main requirements of the research design was a desire to offer flexibility; options to adapt the data collection methods to meet the needs of the participants. Seale et al.'s (2015) participants identified how participatory research required "flexibility, trust, rapport, good relationships and respect" (p.487). Flexibility in research allows the researcher to be responsive to the co-researchers and facilitate their needs and requirements in the research (p.490). Hence, building in opportunities to review and reflect in the research design to check progress and plan the next steps is important.

Flexibility was integral to my design, e.g. by introducing periods of learning separately to trying out new skills. These distinct sub-phases to each phase allowed space to reflect on how the participants reacted to the learning before asking them to engage in the practical skills and adapt these to their needs. This meant that aspects of the original plan were changed to reflect what the co-researchers had said they wanted to do to reach the broad aims of the project. For example, in my initial plan there was only one data analysis session. Yet in the first data analysis session the mood of the group was not productive, and instead the co-researchers found it important to have other conversations unrelated to the project. Adapting to this, I scheduled in another data analysis session to not pressure the co-researchers when they were having important and fruitful conversations on other topics. This adaptive approach, when applied to citizen science, could allow for the participants/co-researchers to become more involved in the process instead of being passive participants. Furthermore, it would give the participants/co-researchers more ownership over the project potentially supporting their engagement. I will discuss this in more detail over the upcoming chapters.

3.4.2 Participants and setting

A key aspect of the research was working with a group of people with learning disabilities in order to introduce them to citizen science and support them to undertake their own citizen science project. I therefore needed to recruit a group of participants with learning disabilities. I chose to do this by contacting the Oxfordshire based charity 'My Life My Choice'. The charity focuses on self-advocacy and they support several self-advocacy groups around Oxfordshire. The charity also engages in local and national campaigns to further the opportunities for people with learning disabilities.

I contacted the leader of the self-advocacy groups to introduce and explain the outline planning for the project. We then met several times to discuss potential aims for the project and how we might go about working together. I attended a meeting where I explained the project to the potential participants and sought their approval to proceed with detailed planning. I then co-produced the sessions (Chapter 4) with the group leader. This identifies elements of upstream planning in co-production (Wilsdon and

Willis, 2004), yet it is also important to note that the co-researchers were not involved in this initial process of the overall PhD study. Instead the My Life My Choice group leader spoke on their behalf for this phase of the study.

The subsequent co-researcher's citizen science project was planned upstream and downstream throughout that research cycle. Initial planning was deliberately flexible, and the co-researchers displayed a level of control over them (Chapter 5).

The co-researchers were members of the Banbury self-advocacy group. (They provided consent to be named as a group). The participant group consisted of adults (over the age of 18), who had a range of learning disabilities. In total 11 co-researchers, including the My Life My Choice group leader, took part. All the co-researchers could communicate and had high levels of engagement within the group, which meant that the co-researchers could engage in discussions about the research.

Group numbers fluctuated from session to session. Over the course of the research at least one member of the group would be absent in each session. This often meant there was a need to recap at the beginning of each session and allow time for extra support for the co-researchers who had been absent previously. One member did not consent to have their data collected as part of the project. The non-consenting member still joined in with the research activities.

Information regarding what types of learning disabilities the participants had was not disclosed to me. I therefore planned in time to learn the different needs and requirements of the co-researchers and be reflexive in my practice. It is important to note that this project wasn't aimed at looking at the individual learning disabilities and fixating on the different medical diagnoses of the participants, instead looking at the learning-disabled community. This removed any need to label ourselves within the group as disabled or non-disabled and create a more equitable environment to build on. I believe by ensuring that co-researchers could participate, and not analysing the learning disabilities of each co-researcher, I was able to create a supportive group environment. This was key to this project, as it allows for open discussions where all parties are equal and treated so (Chapter 7).

In this thesis, I will refer to the co-researchers of the study as P(number). This was after a conversation with the co-researchers, who made it clear they wanted their identities to remain anonymous. As many of the conversations had during this study could potentially identify the co-researchers, I decided to number them to remove any identifiable features. Furthermore, as the group wanted to be recognised

for their work, this allowed us to recognise the My Life My Choice Banbury self-advocacy group, whilst still keeping the individuals anonymity.

3.5 Data Analysis Methods

Kara (2015) claimed that “a common failing of research reports and journal articles is not to explain the process of analysing data clearly enough” (p.99). Following Kara’s remark, this section will provide a comprehensive, but concise overview of my approach to data analysis.

When deciding how to analyse the data, I first considered creative approaches to data analysis. Kara (2015) in her book on creative research methods, discusses how data analysis at its core is a creative process. For example, Braun and Clarke (2019) describe thematic analysis as creating “creative and interpretive stories about the data” (p.594).

Sanger (1994) introduces us to seven types of creativity to be found within data analysis:

1. **“Labels and categories”** – This is best described through Braun and Clarke’s (2019) discussion about thematic analysis; “themes are analytic output developed through and from the creative labour of coding” (p.594). The very process of creating labels, categories or themes is creative as the researcher begins to interpret data and create a story around these.
2. **“Methodological imports”** – This refers to the introduction of methods outside of the field of research.
3. **“Theoretical imports”** – Researchers can challenge their views critically through alternative theories and philosophies.
4. **“Novel methods”** – “Invention of data gathering methods to suit the circumstances” (Sanger, 1994: p.182). For example, in this project, whilst I cannot claim to have ‘invented’ any of my data collection methods, they are adapted to suit the project and my co-researchers. Please refer to Section 3.4 for more detail
5. **“Reporting”** – Writing, is at its core a creative task. It involves a person creating a story, whether that be in a fictional novel or an academic paper. Moreover, Sanger (1994) claims that “the act of writing is an act of analysis” referring to the processes involved in writing, “the ordering, weighing, listing, juxtaposing and bridging of information” (p.183)
6. **“Metaphors”** – Looking at the metaphors within the data, to create an understanding of critical tensions within the community or problem being investigated

7. **“Alien structures”** – Through the adoption of ‘alien’ structures to your data analysis you can learn new things about the research. For example, applying the ‘I’ poem analysis method (Edwards & Weller, 2012: p.205) to conversation data to better understand how participants represent themselves (Kara, 2015).

(quoted in Sanger, 1994: p.179-184)

These seven types of creativity show that even when using more ‘formal’ or ‘traditional’ methods of data analysis there are creative aspects. This project used many of Sanger’s (1994) different types of creativity above throughout the whole process. Starting with “methodological imports” and “novel methods”, where the creative methods employed were not commonly used alongside a citizen science project, moving on to “labels and categories” where the thematic analysis process was wholly creative. Finally, the ‘reporting’ of the project and its data in this thesis.

There is little in the way of literature that discusses the limitations of using a creative approach within research. Indeed, as Kara (2015) suggests, ‘research is a fertile area for creativity’ as both creativity and research are linked with ‘uncertainty’ (p.13-14). This uncertainty was visible in this research, yet it is also what allowed for a reflexive and adaptive process. Furthermore, it created opportunities for unique engagement. An example of this within the context of this study was when co-researchers did not want to, or feel they could, engage with a creative exercise. This created a space in which to discuss and develop new ways of working that suited the groups capacities and built new ones. Creative research in its nature faces the limitation of reproducibility. It is unlikely that different co-researchers would produce the same artefacts and may indeed approach the exercises in a different manner. This again links to Kara’s (2015) discussion of ‘uncertainty’, yet also creates the opportunity for a broader discourse in which further studies, with new and different data, can add to the discussions in this thesis. Creative research, joined with an inclusive approach to data collection, has the potential to create many different forms of data as co-researchers explore their capacities and create data to suit them. This has its limitations in regard to data collection as the researcher, or person engaging in the analysis process, has to analyse across multiple forms of data which takes more time and effort.

In the earlier discussions of data collection methods, I explain how ‘reflexivity’ was key in my process of both deciding on which methods to use and how I employed them within my research (Section 3.3). This was something I considered to be important in my selection of a data analysis method also. In my Masters project (Carr, 2018) I used Braun and Clarke’s (2006) thematic analysis with data similar in nature to that collected in this project. With Braun and Clarke (2019) relabelling this approach as

“reflexive thematic analysis” (p.590), I chose to apply this approach again as it was appropriate with these forms of data.

In their first paper on thematic analysis, Braun and Clarke (2006) described the analysis method as “a method for identifying, analysing and reporting patterns (themes) within data” (p.78). In a later paper, in which the researchers critique their method, Braun and Clarke (2019) “conceptualise themes as patterns of shared meaning underpinned or united by a core concept” (p.593).

One key tension within thematic analysis, is its flexibility. Thematic analysis is described as having a theoretical freedom (Braun and Clarke, 2006 & 2019; Nowell et al. 2017) which allows for it to be used in many different contexts and for it to be conceptualised for each individual project, useful when working with different types of data such as the ones in this project. Yet, this can also be seen as a disadvantage, as this can create space for more scrutiny with no set theory to follow (Holloway & Todres 2003: p.346). In this circumstance, I chose to apply thematic analysis through the lens of Freire’s (1970) critical pedagogy (Section 3.3). Freire’s three dimensions for research; listening, reflecting and engaging, were used in a complimentary way in combination with thematic analysis, thereby creating a process for analysis. By first listening to the data and “engaging with the researcher voices” (Nind & Vinha, 2014: p.103) the person doing the analysis can view the data through the voices of the co-researchers. Then, by employing the second dimension of ‘reflecting’ and “thinking together about those different voices and view” (Nind & Vinha, 2014 (b): p.103), the analysis can focus on creating themes that are reflective of the both the group views and the independent co-researchers view. Lastly, Freire’s final dimension of engaging and “learning from and with each other” (Nind & Vinha, 2014 (b): p.103) finalises the analysis process, with the definition and linking of themes to create a final argument. By applying these dimensions to Braun and Clarke’s (2019) ‘reflexive thematic analysis’, I was able to engage with the different forms of data and reflect on the themes throughout the analysis process.

It is important to note, however, the analysis was both bottom-up (based on the data) and top-down (informed by the research questions). Prior to engaging in thematic analysis, Braun and Clarke suggest the researcher decide on how to progress with the analysis, for example what questions they want to answer (p.82). These refer to the research questions (Chapter 1.1.3).

The principles proposed by Braun & Clarke (2006 and 2019) influenced my initial deductive approach to analysis. I began by looking at my research questions and identified two key themes: support and capacity. Using these, I analysed my data and created a first iteration of coding. The first attempt

began with two themes which had been identified through the research question. After this, the analysis was largely inductive, identifying and consolidating themes from the data. I then chose to look at the data a second time, which was conducted in conjunction with one of my supervisors to verify and validate the codes. From this second round of analysis, several more sub-themes emerged. Through each iteration, the themes became more detailed and more sub-themes emerged from the data. I will discuss them in more detail below.

Below is a table displaying the second of the two iterations of this coding:

Table 3 - Analysis Introduction

Themes	Sub themes	
Support – Different types of support given to the co-researchers during the project	Facilitator	Prompting to focus
		Finding links between ideas
		Technical aspects of the activities
		Ensuring involvement of the co-researcher
		Leading ‘how to do’ the project
	Environment	Number and nature of facilitators
		Routines (Agreed ways of working)
		Location
	Co-researcher	Technical aspects of the activities
		Helping others (who may be struggling) to engage
		Making links to other’s experiences
Capacity – The co-researchers’ abilities to engage in the project, some of these they brought with them, others they developed over the course of the project	Prior experience – To inform discussions and descriptions	
	Engagement	Fully engaged
		Distraction/being off task
		Interest in the task
		Understanding of the task
	Self-advocacy -	
	Advocacy – co-researchers speaking for others	
	Political – showing awareness of local and larger issues	
	Drawing on prior knowledge	
	Agency	Engaging in the project independent of the group
		Taking control of a group activity

		Adapting/shaping tasks to meet own needs and agendas
	Literacy	Inquiry literacy
		Scientific literacy
		Reading and writing
		Research literacy
	Intrapersonal	Disabled identity
		Non-disabled identity

Having described the data analysis methods applied, I will now move on to discuss reliability and validity.

3.6 Reliability and validity

Validity is key to any research project; it is how a researcher can prove that their research was not only worth doing but also impactful. Cohen et al. (2003) highlight the importance of validity claiming that “if a piece of research is invalid then it is worthless” (p.105). Yet how do we judge the validity of a research project and its data? Cohen et al. (2003) suggest we might consider “the honesty, depth, richness and scope of the data achieved, the participants approached, the extent of triangulation and the disinterestedness or objectivity of the researcher” (p.105). Also important in a research project is reliability, which Kara (2015) describes as “the stability of measures” (p.68). In order to measure these, many researchers have created different criteria. When discussing this, Hammersley (2009) claims that it is important these criteria be “open-ended” and “not fully explicit” (p.15) to allow for researchers to use their own judgement. I have selected two sets of criteria: Lincoln and Guba (1985); Nind and Vinha (2012).

Firstly, I will discuss Lincoln and Guba’s (1985) criteria presented above and defend the reliability and validity of this study as a qualitative study.

1. **Confirmability** – Within the researcher observations collected during the study I included a section in which I could reflect on my role within the session and my experience within the

session. During the data analysis process this provided me with the opportunity to understand my influence on the co-researchers and the data collected. Furthermore, in Chapters 4 and 5 I discuss in detail each session and explain how I, as a researcher, felt in these sessions and the impact this may have had on the study.

2. **Dependability** – This study is conducted with 11 co-researchers from two different categories i.e. one worked for My Life My Choice and the others were self-advocates. This in turn means that without trialling, we would not know whether it could have the same results at another time. However, I would argue that the methods and inclusive approach have been proved to be appropriate for the participant group and therefore would have more of a chance of providing similar results with this community. Schofield (2007) discusses this issue, and more widely generalizability and claims that the purpose of any research study is “to produce a coherent and illuminating description and perspective on a situation that is based on and consistent with detailed study of that situation” (p.183). I would argue that this study does that, and this thesis is the ‘coherent and illuminating description’ of the situation being studied.
3. **Credibility** – By describing the methods used and the data analysis process in detail, I aim to provide a believable contribution to knowledge. I argue it is only through a thorough narrative of the entire process of this study that I can offer this and that is the aim of this thesis.
4. **Transferability** – This links to **dependability**, and whether the methods used in this study would be able to be applied in other contexts. This study was aimed specifically at the learning-disabled community. I would argue that by having an inclusive approach at its core, this study could be replicated with other members of the learning-disabled community. Furthermore, through both the inclusive and reflexive approaches used within this study it could be argued that it would suit any context as it is designed with the co-researchers.

The second set of criteria were produced by Nind and Vinha (2012) in a study where they aimed to “build knowledge and capacity” (p.18) in relation to inclusive research. These are presented as a set of questions for a researcher to ask themselves when judging the quality of inclusive research with people with learning disabilities (p.60). Below I list them and make a case for each.

1. **Is the topic relevant to the lives of people with learning disabilities and interesting to them?**
Could it become relevant?

- a. There are two parts to this. As a community, people with learning disabilities have been excluded from the citizen science narrative. I argue in Chapter 2 that this exclusion removes them from having a voice in important scientific inquiry that has potential to have an impact on their lives. Secondly, the citizen science project run in this study is based on a topic decided by the co-researchers with learning disabilities. This ensures that it is relevant to them and the output they have decided on creating (a leaflet – Appendix A) has the potential to benefit the larger learning-disabled community.

2. Does the research involve people with learning disabilities in a meaningful and active way?

- a. This study is based on involving the co-researchers in as much of the research process as possible. Whilst I, a non-learning-disabled researcher planned the sessions they were constantly adapted in reflection of what the co-researchers wanted to do. Furthermore, the co-researchers made the decisions in relation to their own citizen science study with support, so they have total ownership over it.

3. Are the participants in the research treated with respect?

- a. In this study, I did not directly employ any form of evaluative tool to be able to say that the co-researchers in this study did feel respected. However, before beginning the study we created group agreements to dictate how we would work. These matched the agreements already in place in the group one of which is: Be respectful of yourself, others and the place we are meeting in. These were read out each session to remind all of us of our role within these meetings. Furthermore, the methods used within the project were designed to allow for freedom for the co-researchers to respond and take control.

4. Is the research communicated in a way people with learning disabilities can understand and respond to?

- a. The reporting of this research takes several forms. Whilst this thesis is not easy read for those outside the academic community, an easy read document will be produced with the co-researchers support for them to share, alongside the charity My Life My Choice, to show people what we have done together. Furthermore, a leaflet, designed by the co-researchers was in the process of being put together just prior to the Covid-19 pandemic. This was completed by the researcher and disseminated to the co-researchers for approval (refer to Appendix A). Furthermore, the Covid-19 pandemic also halted plans to create a video in which the co-researchers explained what they had done so they could represent their research at academic conferences. By having all three of the outputs described above, the

co-researchers of this study would have been able to connect with different communities and have a wider impact.

5. Is there honesty and transparency about everyone's role and contribution?

- a. Before beginning the sessions, I explained why I was there and what I would be getting out of our partnership. The co-researchers echoed this throughout the study and understood my role there. Furthermore, at the beginning of each session I spoke to the co-researchers about consent and their right to remove it, discussing what data I was collecting and how I would be using it. Yet, I strove to achieve an environment of equality within the sessions, by referring to everyone involved in the sessions as co-researchers instead of participants.

6. Were the ways of working carefully thought through and adapted in response to needs?

- a. In Chapters 4 & 5 I detail the plans I had made prior to beginning the sessions and note how each session was adapted to respond to the co-researchers' needs and wants.

7. Does the research create worthwhile knowledge?

- a. I argue that this research is key to beginning the narrative around the inclusion of people with learning disabilities in citizen science. Furthermore, by detailing the process used and providing a description of my experience as a researcher I hope to inform more researchers on how to remove the barriers currently excluding people with learning disabilities from the citizen science discourse.

8. Are there likely long-term wider benefits for the people involved e.g. new networks, skills, funds, roles, social inclusion?

- a. A large component of this study was aimed at capacity building for the co-researchers. By learning about the research process and conducting their own citizen science study they are able to perform research design, data collection, data analysis and creating outputs in a supportive environment. These skills can be used in their self-advocacy work and therefore have long-term wider benefits for them.

9. Are the research questions the kind that inclusive research can best answer?

- a. I argue that my research questions (Section 1.3), are best suited to an inclusive approach as inclusive research provides an environment in which co-researchers can explore their capacity and identify any support required. Furthermore, it provides situations in which two-way conversations can be had with all parties having the opportunity to control the narrative of the study. That way it is not only the researchers' inference of what the co-researchers think, but their opinion is openly included as well. However, it's important to note that no other research approaches were attempted for this project. The inclusive

approach was selected for this project due to the relationship it has with the learning-disabled community and its focus on equitable power within research.

10. Does the research reach participants, communities and knowledge that other research could not reach?

- a. By including a mixture of research approaches and research methods, this study is unique in its approach. It asks the researcher to constantly be reflexive to the co-researchers' needs and places the co-researchers in control of their own study. This approach has the potential to reach communities previously excluded by acknowledging their differences and adapting to these. It is important to note however, that the unique nature of this research could impact on the reproducibility of the findings. The aim of this thesis is to provide an example of how citizen science, and indeed public engagement more generally could be approached in a more inclusive manner to include the currently excluded communities. The findings of this project can therefore be applied as a guide for future researchers to inform their practice. The reproducibility of these findings therefore is not of concern, and instead, diversity and new knowledge regarding the findings would only add to further the discourse of exclusion within these fields.

11. Does the research use, and reflect on, the insider cultural knowledge of people with learning disabilities?

- a. The co-researchers in this study are asked to create and conduct their own citizen science study. In order to do this, they are asked to reflect on topics with a relevance to them. In doing this, the co-researchers also discussed issues with a wider relevance to not only the learning-disabled community but to other vulnerable groups also. This, I argue, is using their insider cultural knowledge, and providing them with the opportunity to use it to benefit a wider group of people.

12. Is the research genuine and meaningful?

- a. By focusing on topics that have an impact on the co-researchers and by involving them in the entire process, the co-researchers gain complete ownership over the study. Furthermore, by creating an output that they have designed and can share about the research they have conducted they are given the opportunity to share their work which I argue, is a meaningful thing.

13. Will the research make impact that people with learning disabilities value?

- a. The impact of this research has the potential to open a whole field of research to a previously excluded community. By creating a discourse regarding the involvement of people with learning disabilities in citizen science I aim to potentially influence other researchers to continue the discussion and begin to look at more projects involving this community. In turn this will then bring the learning-disabled community into the citizen science discussion.

Through these sets of criteria, I have argued the case for both the validity and the reliability of this project. Firstly, its validity as a qualitative project and how it meets the criteria set out by Lincoln and Guba (1985). Secondly, its quality as an inclusive research project by answering the questions set out by Nind and Vinha (2012). I argue that the detailed descriptions (Chapter 4) will provide further evidence as to the validity and reliability of this project. Next, I discuss the ethical issues linked to this project.

3.7 Ethics

Prior to beginning this project, ethics approval was gained from the Open University's 'Human Research Ethics Committee'. This involved producing a document stating the plan for the project and any supporting documents for the co-researchers e.g. consent forms and information sheets. Approval was granted on 05/11/2018, after suggested corrections were completed, under the reference: HREC/2958/Carr (Appendix B).

During the planning stage of this project three key ethical issues were identified:

1. Working with vulnerable adults
2. Addressing the issue of power
3. Informed consent

I will address each one of these in turn, unpacking the issues and how these were dealt within this research project.

3.7.1 Working with vulnerable adults

One of the key ethical issues was the 'vulnerable' status of the co-researchers and their overall safety within the project. The project itself was on an 'opt-in' basis where the co-researchers had the choice

to join the project, each session will involve informed consent. The co-researchers were encouraged to participate however much or little they wanted too.

Safeguarding is the most common issue when working with people with learning disabilities as within ethical discourse they are perceived as being vulnerable. I addressed this by familiarizing myself with the My Life My Choice safeguarding procedures. When working at Yellow Submarine (an Oxfordshire based learning disability charity), I had undertaken safeguarding training both provided by the charity and the local council. This meant I understood the importance of the procedures for safeguarding the co-researchers. For this project, the safeguarding procedures were to inform the My Life My Choice staff member and ensure no data involving the safeguarding issue was recorded.

3.7.2 Addressing the issue of power

As discussed earlier in the thesis (Chapter 2), inclusive research aims to reduce power barriers within research. The world we live in is based on a hierarchical system: power is not equally distributed. Nind & Vinha (2014b), when reflecting on their project, discuss how even in inclusive research “power dynamic issues have not gone away – they remain live and raw” (p.105), and therefore need to be consciously addressed by all involved in the research. In order to address this issue, I was reflexive in my practice, adapting my role within the group to reflect their needs. As someone without a learning disability it is important to me that I did not use this privileged position to gain the results I need. In my previous Masters project (Carr, 2018) I needed to address the issue of being an ‘insider’ within the charity, already having a certain level of power. In this project, I was initially an outsider. Hammersley and Atkinson (2007) explain, “those defined as outsiders or insiders are likely to have immediate access to different sorts of information” (p.87). In this instance, being an outsider meant it took time for me to build rapport. I anticipated this issue and built in the need to build rapport in my session planning, allowing time at the beginning to join their sessions and get to know the group before establishing myself as the ‘researcher’.

Results from the project was fed back to the participants throughout the project. Furthermore, when circumstances allow, I will arrange to visit the group to discuss the thesis. A short version of this has already taken place as I discussed the thesis and any outputs with the group in one of their regular Zoom meetings.

The My Life My Choice staff often used the power they had within the group to support the engagement of co-researchers, e.g.by encouraging people to participate. Often this was through their

own engagement, as they would team up with someone to enable their engagement. No plans were put in place prior to the sessions to ensure that power wasn't abused by the My Life My Choice staff. On reflection, whilst it was not necessary in this study, it would be a consideration in any future studies where staff members or support workers are involved. It is important to note however that the My Life My Choice staff followed the charity's procedures for safeguarding their members.

3.7.3 Informed consent

This project worked directly with vulnerable adults, meaning that informed consent had to be gained before co-researchers could join. Consent forms were given to co-researchers after the project was explained to them, and they were given the opportunity to ask questions. This consent was revisited throughout at the beginning of each session, with co-researchers being reminded that they can remove their consent should they wish. The consent forms and information sheets were in an easy read format, to enable the co-researchers to read and understand the information themselves.

Within this informed consent the co-researchers were given the choice as to how they are anonymised in the project. Anonymisation was discussed in the first session, and the choice was made collectively. Anonymisation is important as it allows the co-researchers to speak honestly, and without fear. It can, however, be limited in its application. For example, in this thesis I have named the charity and the location of the self-advocacy group (My Life My Choice and Banbury), as these provide the co-researchers with a sense of ownership whilst still being anonymous.

During the course of the project, I received signed consent forms from all of the co-researchers discussed in this thesis.

Both the consent forms and information sheets are provided in Appendices C, D & E.

3.7.4 Research Data Management

Data collected during this study was stored on an Open University laptop and was not transferred. The data was removed from audio and video recorders and stored on an Open University secure server. This will be stored for a period of ten years following the submission of this thesis for examination, and then permanently deleted.

The data collected in this study was recordings of one-to-one and group discussions, photographs (artefacts and groupwork), researcher observation notes, and outputs from groupwork (e.g. survey and

extra research done by co-researchers). This data was anonymised by strategically removing any information which could identify the co-researchers, removing any information relating to safeguarding issues and ensuring names were changed.

The analysis and coding process took place throughout the period of data collection (12 months) in which I coded data both deductively and inductively. For more detail on the process, see Section 3.5

3.8 Summary

In this chapter I have outlined the methodology and methods used in this project. First, I began by introducing the critical research paradigm highlighting how the focus on investigating the “taken for granted” (Clough & Nutbrown, 2007: p.17) reflected the inclusive aims of the project discussed in this thesis. Furthermore, I introduced Freire’s (1970) three dimensions for research and discussed their influence on inclusive research and therefore, this project. Next, I introduced the different data collection methods used within this project. I discussed at length the different ‘traditional’ qualitative methods used and my justifications for combining them with creative methods to allow for more comprehensive data collection. From this, I introduced the context this project was conducted in. Firstly, I discussed the research design, looking at the different phases of my project and how it developed throughout the process. Next, I discussed in detail the process of recruiting the co-researchers for this project and the nature of both the co-researchers engaged in the project and the setting in which it was conducted.

From this, I moved on to provide an outline of my data analysis methods, introducing my analytic framework and how I came to create it. I then followed this by discussing the reliability and validity of my project. One key issue raised, was the generalisability of this project. The process adopted in this project will enable future research to be conducted. The focus is on beginning a discourse and creating opportunities for engagement of a previously under-represented and currently excluded community. Whilst, during the discussions of the findings (Chapters 5,6 and 7) I will refer to the learning-disabled community in general, it’s important to note that these are suggestions of ways researchers can approach and work alongside them. Next, I looked at how I planned to manage my research data in order to ensure it was stored in the safest way possible for my co-researchers. Finally, I discussed the ethical issues that were a key consideration in my project, working with vulnerable adults, addressing the issue of power and informed consent. I provided justifications for how I approached these issues and dealt with them in my project.

Having discussed my methodology, I will now move on to discuss the capacity building programme employed during this project.

Chapter 4 – Capacity Building Programme

4.1 Introduction

In this chapter the methods used in the three phases of this project are presented, along with a detailed description of the 11 sessions. This will provide context for Chapters 5, 6 and 7 in which I present my findings and discuss my conclusions.

In this chapter I will also discuss some of the initial findings from the data collection. I have noted the need to be flexible in building capacity using an inclusive research approach. Interweaving initial findings in this chapter, highlights my reflexive approach. Initial findings from each session informed later data collection methods and show how the sessions were adapted to the co-researchers' needs.

The first phase of this project provided the groundwork for the co-researchers to build capacity to enable them to conduct their own research project (Table 2). Through the literature review I established a need to focus on identity and offer a space for the co-researchers to explore this. Furthermore, I used creative research methods to establish an environment in which the co-researchers could learn about citizen science and how they could be citizen scientists.

The second phase of this project was aimed at the co-researchers planning and conducting their project in a supportive environment (Table 2). In the literature review, I described a lack of a pedagogical framework for capacity building with people with learning disabilities (Chapter 2.7). Phase 2 provided relative freedom when planning this project, supporting adaption to co-researcher's capacity needs. As the co-researcher's confidence and capacity ebbed and flowed, scaffolding could be withdrawn or reintroduced in kind.

When designing this project, I had originally planned two final sessions in the third phase which would give the co-researchers the opportunity to reflect on their experiences and self-evaluate their capacities (Table 2). Due to Covid-19 restrictions these sessions had to be cancelled. I will discuss this in more detail later (Section 4.4).

4.2 Phase 1: Building Capacity

The first phase consisted of three sessions (Tables 4, 5 and 6). Firstly, I will outline the initial session (Table 4), looking at the methods used and any changes to the plan explained in Table 1. Next, I will

outline Sessions 2 and 3 (Tables 5 & 6). I have chosen to discuss these two sessions together as the methods used crossed over between the sessions.

Table 4 – Phase 1, Session 1

Session #1	<u>Phase 1: Session 1 What is research?</u>
Roles	<p>Team building: Whilst JC introduces the activity, the entire group participate in describing what research means to them. This helps the group to understand each other's views.</p> <p>JC and Participants = participant - facilitator</p> <p>MLMC staff/support workers – Choose to either support the participants with making their collages or make their own collage</p>
Activities	<p>Explanation of project: 10 mins JC give out information sheets about the project – group either read these out loud, on their own, or JC gave them an explanation there and then</p> <p>What is consent: 15 mins What do we think consent means? – Shout out words and write on flipchart JC to explain and stress the importance of withdrawing consent at any point during the project JC to give out consent forms</p> <p>Group Agreements: 5-10 mins As a group, do we think we need any extra agreements to support us when we do this project? E.g. Treat each other equally</p> <p>Collage yourself: 30 mins Using newspapers and magazines answer the question – ‘What does research mean to you?’ Each person including JC explains their collage in the group – this was audio recorded to capture the data (if they don't want to do it in a group, this can be facilitated by explaining it to just JC or just a voice recorder)</p>
Data collection & types of data collected	<p>Artefacts – Collages and flipchart recordings of the explanations e.g. Word association</p> <ul style="list-style-type: none"> Supported by recordings of discussions <p>Recording and transcript of group discussion.</p> <p>Participants reflections</p> <p>JC Reflective journals – post session JC will reflect and evaluate how the session went from her perspective.</p> <p>Photographs/short videos will be taken during the session to support JC reflective journals.</p>
Outputs	<p>Informed consent</p> <p>The group gains an understanding of what research is – and what each other think of it</p> <p>A way of working inclusively as a group</p> <p>Baseline data on understanding/experience of research</p>
Research Question	<p>RQa. How do people with learning disabilities understand research as a process that underpins citizen science?</p>

Table 5 – Phase 1, Session 2

Session #2	<u>Phase 1: Session 2 Identity in research</u>
Roles	<p>JC: Participant facilitator – JC to introduce activities and partake in them</p> <p>Participants: Co-researchers – Participants to partake in the activities but also be leading discussions</p> <p>MLMC staff/support workers – Can either choose to support participants or join in the activities themselves</p>
Activities	<p>What is a citizen? 5 mins Have up on a wall easy words to explain a citizen – JC to have a collage of what a citizen is with a simple explanation</p> <p>Identity boxes 30 mins JC to offer an example one. A collection of shoeboxes and craft materials. The participants use these to convey their identity as a citizen Each participant then describes their boxes</p> <p>Draw a (citizen) scientist 30 mins Each participant is asked to draw how they see themselves as the type of scientist they think they are or could be. During this exercise, the participants will be asked to tell a story about their scientists, JC will gather this data by asking the participants one on one about their drawings. The participants will be shown a video of a citizen science project. They will then be asked to draw what they believe a citizen scientist is – followed by identifying the differences – JC to offer an illustration. Discussion to follow about our drawings. In addition, these drawings will then be used as the participant’s ‘avatars’ throughout the remaining sessions – these will be placed along a timeline to identify whether they attended a session or not. They will be given the opportunity to adapt these over the process, as their views of citizen scientists adapt.</p>
Data collection & types of data collected	<p>Artefacts – Collages and flipchart recordings of the explanations e.g. Word association</p> <ul style="list-style-type: none"> Supported by recordings of discussions <p>Recording and transcript of group discussion. Forms of ‘annotation’ (e.g. spoken/written/drawn) to explore experiences/understanding of types of CI research Participants reflections JC Reflective journals – post session JC will reflect and evaluate how the session went from her perspective. Photographs/short videos will be taken during the session to support JC reflective journals.</p>
Outputs	<p>Informed consent</p> <p>The group gains an understanding of what research is – and what each other think of it</p> <p>A way of working inclusively as a group</p> <p>Baseline data on understanding/experience of research</p>
Research Question	<p>RQa. How do people with learning disabilities understand research as a process that underpins citizen science?</p>

Table 6 – Phase 1, Session 3

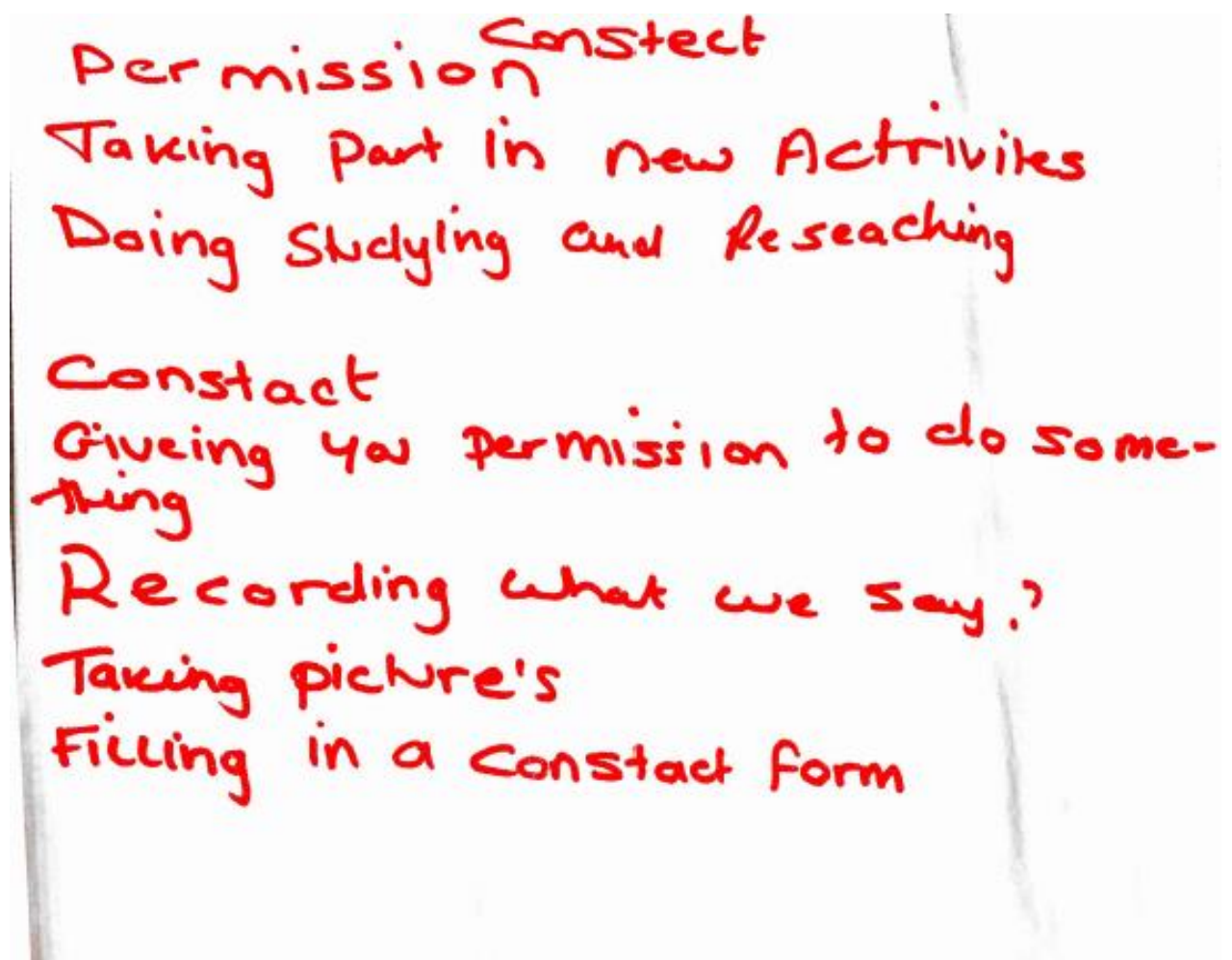
Session # 3	<u>Phase 1: Session 3 How to do research</u>
Roles	<p>JC: Participant facilitator – JC to introduce activities and partake in them</p> <p>Participants: Co-researchers – Participants to partake in the activities but also be leading discussions</p> <p>MLMC staff/support workers – Can either choose to support participants or join in the activities themselves</p>
Activities	<p>Reflections: 15-20 mins –</p> <p>At the beginning of the session the participants will be invited to reflect on the previous sessions in one of three ways:</p> <ol style="list-style-type: none"> 1) Draw a picture – supported with an explanation 2) Write a blog post/ Record a vlog 3) Annotate/drawn on a premade picture <p>The aim of these reflections is to find where capacity is lacking</p> <p>Informal debrief – where the participants can discuss the session and what is happening next month</p> <p>Identity Box continuation</p> <p>Continuing the exercise from last time, asking the participants to further their identity boxes to include topics they want to research – the aim of this will be to prompt a discussion about deciding on topics we want to research (how many)</p> <p>What tools can we use to research? Each person come up with one tool and write it on a piece of paper. These will be put up together on a flipchart – these are the tools we would use.</p> <p>Do some research about your topic using the tools we discussed and write about why you want to research into your topic</p>
Data collection & types of data collected	<p>Group discussion</p> <ul style="list-style-type: none"> • Recording (audio) of group discussion <p>List of tools</p> <p>Reflections/pictures</p> <p>JC Reflective journals</p> <p>Photographs Research plans:</p>
Outputs	<p>Informed consent</p> <p>Data on understanding of research and how it's done</p> <p>Data on capacity to build a research plan</p> <p>Baseline data on capacity to do research</p> <p>Data on capacity within the project</p>
Research Question	<p>RQ. What support do people with learning disabilities require regarding their capacity to engage with citizen science?</p> <p>RQa. How do people with learning disabilities understand research as a process that underpins citizen science?</p>

4.2.1 Phase 1, Session 1: Collage Yourself

Phase 1, Session 1 (Table 4) focused on an introduction to the project for the co-researchers. It began with discussing consent and its meaning within the context of this project. The co-researchers identified the different things to which they may need to consent, e.g. recording, pictures. They also showed their understanding of the word and the importance of consent within this context (Figure 4).

Four of the members of the group consented at the session whilst others took the consent forms home to discuss with support workers and/or family members. These co-researchers did not bring their consent forms (Appendix C) back but told me they had spoken to their support workers and/or family members and were happy to provide consent in the following sessions (see Section 3.7.3 for more detail).

Figure 4 - Exploring ideas about consent, using a flipchart



For the next activity of the first session, the co-researchers were asked to engage in an activity entitled ‘Collage Yourself’ (Section 3.3.1). I adapted the exercise to ask the co-researchers to convey their feelings and opinions about what research means to them. Prior to beginning our research project, I wanted the group to capture what research meant to them both individually and as a group. Furthermore, I adapted the ‘Collage Yourself’ exercise to offer an exercise for the co-researchers to partake in that would begin discussions.

When presenting the activity, I showed a few examples produced by Open University PhD students who engaged in a practice session I ran for my methods (Chapter 3.3.1). These collages focused mainly on the research process. This differed to the co-researchers’ understanding of the task and conveys how the activity can be interpreted in many ways, dependent on the motivations of the group. I will discuss the data collected in this session Chapters 5 and 6. I will now move on to discuss Sessions 2 (Table 5) and 3 (Table 6) from Phase 1.

4.2.2 Sessions 2 & 3

Sessions 2 and 3 were aimed at encouraging the co-researchers to define citizens. Through this, the co-researchers were supported in creating their identities, both as a citizen and within research. I used a selection of exercises during these sessions to scaffold the discussions and allow the co-researchers to explore citizenship.

Phase 1, Session 2, Exercise 1: What is a citizen?

The original plan for the second session (Table 5) was adapted due to time constraints; we spent more time on the ‘What is a citizen?’ discussion, leaving less time for identity boxes and no time for reflections. In later sessions the co-researchers conveyed that they did not want to reflect on each session, instead they preferred spending more time on the activities. The plans were adapted to suit this and reflecting became the primary focus of the third phase of the project. To begin with we had an open discussion about how we, as a group defined citizenship.

This session was based on Morris’ (2005, Section 2.3.2) three concepts of citizenship: self-determination, contribution, and participation. These themes link to the definition of what a citizen is that the co-researchers created. They broke their definition down into three categories:

Personality traits:

- Assertive with each other
- Allocating
- Working with each other
- Confiding
- Helps you
- Looks after you

Caring Professions

- Nurse
- Doctor
- Parent

Self-advocacy:

- Us
- This group
- Being more assertive

The first theme, personality traits, focused mainly on positive characteristics e.g. “helps you, working with each other, confiding” (P1). These mostly convey a citizen as a caring person, who focuses on their community. The second theme, caring professions, came about after much of the discussion focused on the co-researcher’s recent experiences with doctors and nurses, prompted by one co-researcher (P4). This co-researcher expressed how doctors and nurses cared for other people within the community and used them as an example of a citizen. The third theme, self-advocacy, focuses on how the co-researchers identified as citizens themselves. However, it is important to note that before being prompted only one co-researcher (P6) identified that they counted as citizens. After being prompted that they had not mentioned this in their discussion all the co-researchers agreed with the statement with P1 claiming “well we’re a citizen we’re sitting here doing this group”. P4 agreed with this statement stating, “I was gonna say me, nurses and, [us] but I couldn’t say all three” (What is a citizen_Session_2).

All three of Morris' themes link to the co-researcher's identification of self-advocacy. The co-researchers described being a citizen as being a self-advocate within their community. Self-advocacy requires a level of self-determination, where people begin to take control of issues that affect their lives and community. Furthermore, being a self-advocate means contributing to your community and participating in discussions around issues affecting them. The co-researchers in this project furthered Morris' (2005) definition by identifying the caring nature of a citizen, and the importance of working collaboratively to help their community. The co-researchers also added that citizens are defined by their positive personality traits. Again, these focus on a sense of community, and working together.

Within the first session, the participants identified three aims of research; stop (to bring an end to an issue), improve (improve local systems) and help (assist vulnerable communities). These conveyed their altruistic motivations to do research and link to Morris' (2005) three concepts of citizenship. The aims of 'stop', 'improve' and 'help' all have links to the ideas of 'contribution'. These aims all provide a contribution to both their community and other communities. These altruistic motivations and the acknowledgment of how the co-researchers wish to have a voice in the research, link to Morris' concepts of 'self-determination' and 'participation'. This is important as here we can link the co-researcher's motivations to a concept of citizenship. The co-researchers are conveying who they are as citizens within research and linking both what they believe directs research and what they believe a citizen should be. This creates a link to citizen science, and their identities as citizen scientists.

I will now move on to discuss the activities employed in Phase 1, Sessions 2 and 3.

Phase 1, Session 2, Exercise 2: What is a scientist/citizen scientist

When partaking in a citizen science project, you are a 'citizen scientist'. Silvertown (2009) defines a citizen scientist as a "volunteer who collects and/or processes data as part of a scientific enquiry" (p.467). This definition identifies those participating as a 'volunteer' which contradicts the inclusive nature of this project. Therefore, it was important that within this project, the co-researchers identified with this term in a way that still highlighted their level of control.

When planning Session 2, I planned to do the 'draw-a-scientist' activity (Chambers, 1983). However, during the session only Participant 6 was able to complete the exercise due to timing constraints (Table 5). This was largely due to the fact the other co-researchers were

more engaged with the identity box exercise, which I will discuss in more detail below. To still get the co-researchers to reflect on what a scientist is, I encouraged them to engage in a discussion focusing on their descriptions of a scientist. We began by having Participant 6 discussing their drawing of a scientist, followed by discussion and reflection on the part of the other co-researchers.

During the discussion, the co-researchers defined a scientist in four ways:

Brainstorming – Coming up with new ideas

Being more creative

Short

Lab coat

(Scientist discussion_S2)

Two of these descriptions focus on what a scientist ‘looks’ like i.e. ‘short’ and a ‘lab coat’. The other two focus on how scientists ‘think’ i.e. ‘being more creative’ and ‘brainstorming’. Participant 1 mentioned how they saw a scientist as ‘being more creative’ linking it to ‘what we’re doing here’ (Scientist discussion_S2), ‘here’ meaning in our sessions. This conveys how P1 was linking the sessions to research and more generally scientific activities. My intentions when planning this exercise were to explore the co-researcher’s experiences and knowledge about being a scientist.

In Chapter 1.1.2 I discussed my Masters project (Carr, 2018) where the word ‘science’ seemed to put many potential co-researchers off engaging in my project. One participant claimed, “do you know what, I actually didn’t like science at school, ‘cos all we were doing was writing and it was sort of boring” (p.30). Later in my Masters project the same participant claimed that “[I] feel like I’ve been a researcher my whole life” (p.30). Whilst this was clearly impactful for this participant, I wanted to approach these preconceptions of science and scientists early in this project so that the co-researchers could understand their identity and role within science and research more broadly.

In a project conducted by Anderson & Bigby (2015), the researchers looked at the impact of self-advocacy on the social identities of people with learning disabilities. Through a range of

interviews, the participants identified how through a sense of collegiality within the groups they felt empowered to be self-advocates. This, I argue, relates to the importance of the co-researchers' understanding their social identities within science and research. My argument is that, if co-researchers feel a sense of collegiality and belonging within these fields, they can be empowered to participate and become advocates for the learning-disabled community.

Finally, I asked the co-researchers what they thought a 'citizen scientist' looks like. Participant 1 claimed "one of us", which the rest of the group agreed with. This suggests that the co-researchers are linking the inclusive activities to citizen science, and are identifying, at least, as citizen scientists themselves. I argue that this was influenced by the previous exercise where the co-researchers were asked to look at what a citizen is, where after being prompted, they identified as a citizen themselves. This identified how we had begun to build a shared understanding, creating a foundation on which to build on in terms of capacity building. The co-researchers of this project displayed their ability to link these terms to themselves prior to this, when highlighting their own personal experiences to science.

I will now move on to look at the third and final exercise used within these sessions, the identity box.

Phase 1, Sessions 2 & 3, Exercise 3: Identity boxes

Session 3 focused on the preparation of identity boxes (Figure 5). This was what the co-researchers had requested in the previous session; the identity boxes were clearly very important to them.

Figure 5 - An example of an Identity box



This is an exercise I adapted from Brown (2016) to work in this context (Section 3.3.1). Richards et al. (2019) used arts and crafts in a similar way to this study highlighting how using more creative methods with adults with learning disabilities can be used to enable an opportunity to “convey thoughts and feelings in a way that is accessible” (p.207). Furthermore, Richards et al. (2019) highlight how these creative methods “can be used to represent how identity is represented in society and to share stories about life” (p.206). Similar to the exercise described above, the co-researchers in Richards et al.’s (2019) study were given freedom to use any materials provided with no restrictions on what to do. This, one of the co-researchers argued, was empowering.

Using this exercise, I wanted to provide the co-researchers the space to explore their identity before progressing with the project. This way, they would define what they believed a citizen was, by defining themselves.

4.2.3 Discussion of Phase 1 (Sessions 1 to 3)

In Section 4.2.1, I discussed the different methods used within the first phase of this project (Session 1 to 3). I highlighted how, through these methods, we worked to create definitions around the key themes of this project, research, science and identity. For the co-researchers, many of these definitions focused on what motivated them, highlighting both their focus on self-advocacy and the need to help others. Here, I will highlight how these initial sessions informed the later sessions.

In the first session, the collaging activity allowed the co-researchers to explore their own meanings of research. The collages largely focused on topics with a personal relevance, but they also identified a need to help others outside of their community. Through these collages, the co-researchers showed that a person can have many different motivations for engaging in research, however having a personal link to the research topic was important to them. In a project by Schwartz (2020), one of the co-researchers in the project identified the importance “of relevant lived experiences such as self-advocacy” (p.239) when engaging in inclusive research collaborations.

The co-researchers in this project are part of a self-advocacy group, and therefore have a wider knowledge of the issues facing their community. Whilst in Schwartz’s study this was identified as a positive, and indeed largely reflects the inclusive research principles (Walmsley & Johnson, 2003), these ‘lived experiences’ have an impact on the topic choice and may limit the co-researchers to only focusing on research topics that impact their community. Yet, the methods presented above shows how the co-researchers focused not only on topics with a relevance to their community, but topics which affected many other communities also, bullying, knife crime, animal cruelty and hospitals. By identifying this need the co-researchers showed an understanding of not only the learning-disabled community, but of the other communities around them. Mahony (2015) reflects on the idea that within public engagement there are different roles that citizens play. One of these, is that of the “activist”, i.e. “people opposed to or marginalized from aspects of the status quo” (p.4). It is these citizens who engage in public engagement activities targets at challenging “prevailing public discourses, imbalances of power or dominant social groups” (p.4). The co-researchers of this study took on this role, bringing their own confidence through lived experiences of the issues also facing other communities.

The second session looked at defining the terms, ‘citizen’, ‘scientist’ and ‘citizen scientist’. In the discussions around these terms, the co-researchers recognised qualities that matched who they were and were able to define themselves as all of these. This conveys an understanding of their identity, and how each person fits into different boxes. This led into the identity boxes where the co-researchers were asked to show their identity in a shoebox. The co-researchers framed their identities through their hobbies and things they liked to do. Yet, none of the co-researchers put anything about their disability into the box. There were discussions around disability, however, these did not necessarily focus on identity. This links to Beart’s (2005) concept that ‘learning disability’ is not seen as a ‘salient identity’ by the community. Instead, people with learning disabilities opt to identify themselves via different parts of who they are e.g. personal tastes.

This section has focused on providing the methods and context of the data collected within this project. Here, I have presented the first phase of the capacity building programme, session by session. I will now move on to look at the second phase of the data collection.

4.3 Phase 2 (Sessions 4-11): Planning and conducting the citizen science project

4.3.1 Introduction

In this section, I will describe the second phase of this project. I will outline the methods used within this second phase and discuss the way in which the co-researchers reacted to these. I will detail the plans made prior to engaging in the project and how these were forced to adapt as the project continued. I will work through each session and outline the methods used (Tables 7-14). Sessions 4, 5 & 6 focused on the planning of the research and preparing their data collection method. Sessions 7, 8 & 9 focused on data analysis, with session 7 being an introductory session for the co-researchers. Finally, sessions 10 & 11 offered the co-researchers the opportunity to finalise their analysis and begin to write it up to present their output.

Phase 2 took place over the course of 10 months, with a two-month gap for other My Life My Choice activities. Over the course of the second phase, I found that my plans (Tables 7-14) needed to be less detailed as the co-researcher’s capacity to conduct research grew and they took more ownership of the planning and action.

Table 7 – Phase 2, Session 4

Session #4	Phase 2: Session 4 How we will do research
Roles	<p>JC: Participant facilitator – JC to introduce activities and partake in them</p> <p>Participants: Co-researchers – Participants to partake in the activities but also be leading discussions</p> <p>MLMC staff/support workers – Can either choose to support participants or join in the activities themselves</p>
Activities	<p>nQuire 30 mins – Try out all the different methods of data collection – which one do we think will suit our research study best? Group discussion the ways we think JC has collected data during this study – one person notes any methods that come out of this</p> <p>Research Questions 30 mins – We know our topic – what question do we want to answer about it (May already have this – if so, move onto next exercise) What questions do we need to look at before we research e.g., how many data sets do we need? – small group discussions where we discuss these, write them down on a sheet of paper – feed back to the group.</p> <p>1) Write which ones you feel appropriate onto your research plan</p>
Data collection & types of data collected	<p>Group discussion</p> <ul style="list-style-type: none"> • Recording (video and audio) of group discussion • Supported by notes <p>List of tools</p> <p>Reflections/pictures</p> <p>JC Reflective journals – post session JC will reflect and evaluate how the session went from her perspective.</p> <p>Photographs/short videos will be taken during the session to support JC reflective journals.</p> <p>Research plan:</p> <ul style="list-style-type: none"> • Supported by notes taken by JC
Outputs	<p>Informed consent</p> <p>Data on understanding of research and how it's done</p> <p>Data on capacity to build a research plan</p> <p>Baseline data on capacity to do research</p> <p>Data on capacity within the project</p>
Research Question	<p>RQ. What support do people with learning disabilities require in regard to their capacity to engage with citizen science?</p> <p>RQa. How do people with learning disabilities understand research as a process that underpins citizen science?</p>

Table 8 – Phase 2, Session 5

Session #5	Phase 2: Session 5 Research Topic
Roles	JC and co-researchers – They will be creating their own research plans and will be running group discussions. MLMC staff/support workers – Can either choose to support participants or join in the activities themselves
Activities	Research Questions Session Participants from previous session to share ideas for our research topics. In this session we need to: <ul style="list-style-type: none"> • Narrow down research question • Assign roles and tasks within the groups • Narrow down how are we doing our research? • Prepare for data collection next session
Data collection & types of data collected	JC Reflective journals – post session JC will reflect and evaluate how the session went from her perspective. Photographs/short videos will be taken during the session to support JC reflective journals. Group discussion <ul style="list-style-type: none"> • Recording (audio and visual) • Supported by notes Research plan
Outputs	Informed consent Data on capacity to build a research plan
Research Question	RQ. What support do people with learning disabilities require regarding their capacity to engage with citizen science? RQa. How do people with learning disabilities understand research as a process that underpins citizen science? RQb. Does a structured approach to capacity building support people with learning disabilities in their engagement with the research processes? RQc. Do methods derived from inclusive research support engagement for people with learning disabilities with citizen science

Table 9 – Phase 2, Session 6

Session #6	<u>Phase 2: Session 6 Data collection</u>
Roles	JC and co-researchers – They will be creating their own research plans and will be running group discussions. MLMC staff/support workers – Can either choose to support participants or join in the activities themselves
Activities	<p>If necessary, revisit final exercise from Session 5 – Fill in rest of group on our ideas for data collection</p> <p>Are we doing both buses project and animals project? If so, buses group split off and work on filling in the research plan</p> <p>Collate all our research that we’ve done on dogs and cats since last session</p> <ul style="list-style-type: none"> • Do these answer our research questions? • Which questions are left? Can we answer them through our survey? <p>DATA COLLECTION 1 hr</p> <ul style="list-style-type: none"> • Using your research plan collect data on the nQuire platform. • Write survey to send out to vets • What information are we aiming to get from them? • How many vets do we want to send it to? • Send it out to the vets with a message
Data collection & types of data collected	<p>Data collected on nQuire platform</p> <p>JC Reflective journals – post session JC will reflect and evaluate how the session went from her perspective.</p> <ul style="list-style-type: none"> • Photographs/short videos will be taken during the session to support JC reflective journals
Outputs	<p>Informed consent</p> <p>Data on capacity to build a research plan</p>
Research Question	<p>RQ. What support do people with learning disabilities require regarding their capacity to engage with citizen science?</p> <p>RQc. Do methods derived from inclusive research support engagement for people with learning disabilities with citizen science</p>

Table 10 – Phase 2, Session 7

Session #7	<u>Phase 2: Session 7 Data analysis</u>
Roles	JC and co-researchers – They will be creating their own research plans and will be running group discussions. MLMC staff/support workers – Can either choose to support participants or join in the activities themselves
Activities	<p>Example of analysis 15 mins How many people with blonde, brown etc hair in the room? Which one do we have the most of?</p> <p>Analyse into groups (Common threads) 30 mins Individually organise the pictures (of people) into groups – there are no right or wrong answers and there are no specific groups – e.g you could organise by hair colour, emotion, gender or anything else you can think of. Afterwards we'll discuss our analysis</p> <p>How will we analyse our own data? 30 mins</p> <ul style="list-style-type: none"> • What is the big question we want to answer? • Which analysis method helps us answer that?
Data collection & types of data collected	<p>Examples of research analysis</p> <p>JC Reflective journals – post session JC will reflect and evaluate how the session went from her perspective.</p> <ul style="list-style-type: none"> • Photographs/short videos will be taken during the session to support JC reflective journals
Outputs	<p>Informed consent</p> <p>Data on capacity to build a research plan</p> <p>Data on capacity to do analysis and their understanding of</p>
Research Question	<p>RQ. What support do people with learning disabilities require regarding their capacity to engage with citizen science?</p> <p>RQc. Do methods derived from inclusive research support engagement for people with learning disabilities with citizen science</p>

Table 11 – Phase 2, Session 8

Session #8	<u>Phase 2: Session 8 Data analysis</u>
Roles	JC and co-researchers – They will be creating their own research plans and will be running group discussions. MLMC staff/support workers – Can either choose to support participants or join in the activities themselves
Activities	Recap of previous session – 15 mins Discussion about analysis and recap how we are going to analysis our data Data analysis – 40 mins Analyse our data: <ul style="list-style-type: none"> • Break into small groups • Look at one question each and try to group the answers together • JC to provide an example
Data collection & types of data collected	Analysis of the data Reflections/pictures JC Reflective journals – post session JC will reflect and evaluate how the session went from her perspective. Photographs/short videos will be taken during the session to support JC reflective journals
Outputs	Informed consent Data on capacity to build a research plan Data on capacity to do analysis and their understanding of it
Research Question	RQ. What support do people with learning disabilities require regarding their capacity to engage with citizen science? RQc. Do methods derived from inclusive research support engagement for people with learning disabilities with citizen science

Table 12 – Phase 2, Session 9

Session #9	<u>Phase 2: Session 9 Data analysis</u>
Roles	JC and co-researchers – They will be creating their own research plans and will be running group discussions. MLMC staff/support workers – Can either choose to support participants or join in the activities themselves
Activities	Recap of previous session – 15 mins Discussion about analysis and recap how we are going to analysis our data Data analysis – 30 mins Analyse our data: <ul style="list-style-type: none"> • Break into small groups • Do some extra research on the questions that we were unsure of Write up – 10 mins <ul style="list-style-type: none"> • Putting our research into writing • Split into small groups and write up each answer using our analysis
Data collection & types of data collected	Analysis of the data Reflections/pictures JC Reflective journals – post session JC will reflect and evaluate how the session went from her perspective. Photographs/short videos will be taken during the session to support JC reflective journals
Outputs	Informed consent Data on capacity to build a research plan Data on capacity to do analysis and their understanding of it
Research Question	RQ. What support do people with learning disabilities require regarding their capacity to engage with citizen science? RQc. Do methods derived from inclusive research support engagement for people with learning disabilities with citizen science

Table 13 – Phase 2, Session 10

Session #10	<u>Phase 2: Session 10 Data analysis & write up</u>
Roles	JC and co-researchers – They will be creating their own research plans and will be running group discussions. MLMC staff/support workers – Can either choose to support participants or join in the activities themselves
Activities	Recap of previous session – 15 mins Discussion about analysis and recap how we are going to analysis our data Data analysis – 30 mins Analyse our data: <ul style="list-style-type: none"> • Break into small groups • Do some extra research on the questions that we were unsure of Write up – 10 mins <ul style="list-style-type: none"> • Putting our research into writing • Split into small groups and write up each answer using our analysis
Data collection & types of data collected	Analysis of the data Reflections/pictures JC Reflective journals – post session JC will reflect and evaluate how the session went from her perspective. Photographs/short videos will be taken during the session to support JC reflective journals
Outputs	Informed consent Data on capacity to build a research plan Data on capacity to do analysis and their understanding of it
Research Question	RQ. What support do people with learning disabilities require regarding their capacity to engage with citizen science? RQc. Do methods derived from inclusive research support engagement for people with learning disabilities with citizen science

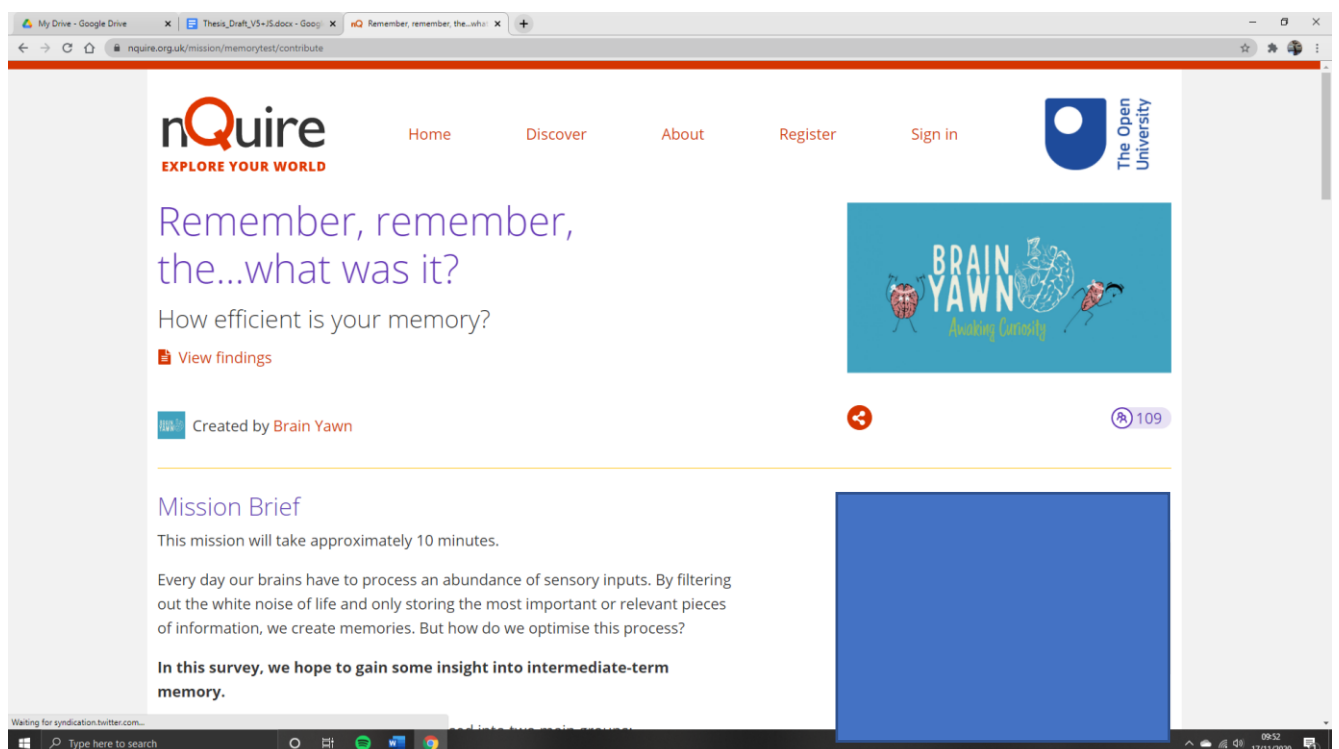
Table 14 – Phase 2, Session 11

Session #11	<u>Phase 2: Session 11 Write up</u>
Roles	JC and co-researchers – They will be creating their own research plans and will be running group discussions. MLMC staff/support workers – Can either choose to support participants or join in the activities themselves
Activities	Recap of previous session – 15 mins Discussion about analysis and recap how we are going to analysis our data Pick a leaflet design – 15 mins (during coffee break) Extra research – 45 mins <ul style="list-style-type: none"> • P4 and any others to continue their extra research from where they left off • Then put any information into an easy read format Inputting data into leaflet format – 45 mins <ul style="list-style-type: none"> • Another group to begin putting the easy read data into the leaflet format.
Data collection & types of data collected	Photographs/short videos will be taken during the session to support JC reflective journals JC Reflective journals – post session JC will reflect and evaluate how the session went from her perspective.
Outputs	Informed consent Data on capacity to build a research plan Data on capacity to do analysis and their understanding of it
Research Question	RQ. What support do people with learning disabilities require regarding their capacity to engage with citizen science? RQc. Do methods derived from inclusive research support engagement for people with learning disabilities with citizen science

4.3.2 Phase 2, Session 4: Planning & nQuire

Session 4 was focused on the co-researchers starting to plan their research project. In order to do this, I showed them a citizen science platform, called nQuire (<https://nquire.org.uk/>). This platform, created in collaboration between the BBC and the Open University, offers a step-by-step approach to delivering scientific inquiry projects. Discussing previous iterations of the platform, Herodotou et al. (2018) highlight the scaffolded approach taken by nQuire and make suggestions for future inquiry-based learning platforms. When discussing the nQuire platform, they outline the process of inquiry for the online investigations: “setting their research objectives, devising a methodology, collection and analysing data, and reaching a conclusion” (p.6). In the current iteration of the nQuire platform, there are two types of inquiry a user could engage with: confidential and social. Confidential missions concentrate on surveys which allow the user to discover more about themselves (Figure 6). In contrast social missions offer users the opportunity to contribute their own explorations of a topic, such as mapping the noise levels of workspaces.

Figure 6 - nQuire Confidential Mission



I chose to use nQuire, having used it successfully during my Masters study (Carr, 2018). In that earlier study, I had wanted to explore whether the platform could support capacity building by offering a structured approach. I found it explained the process of research and

offered a supportive practice space for the co-researchers in that project and that, the platform had space for users to create their own missions (Carr, 2018).

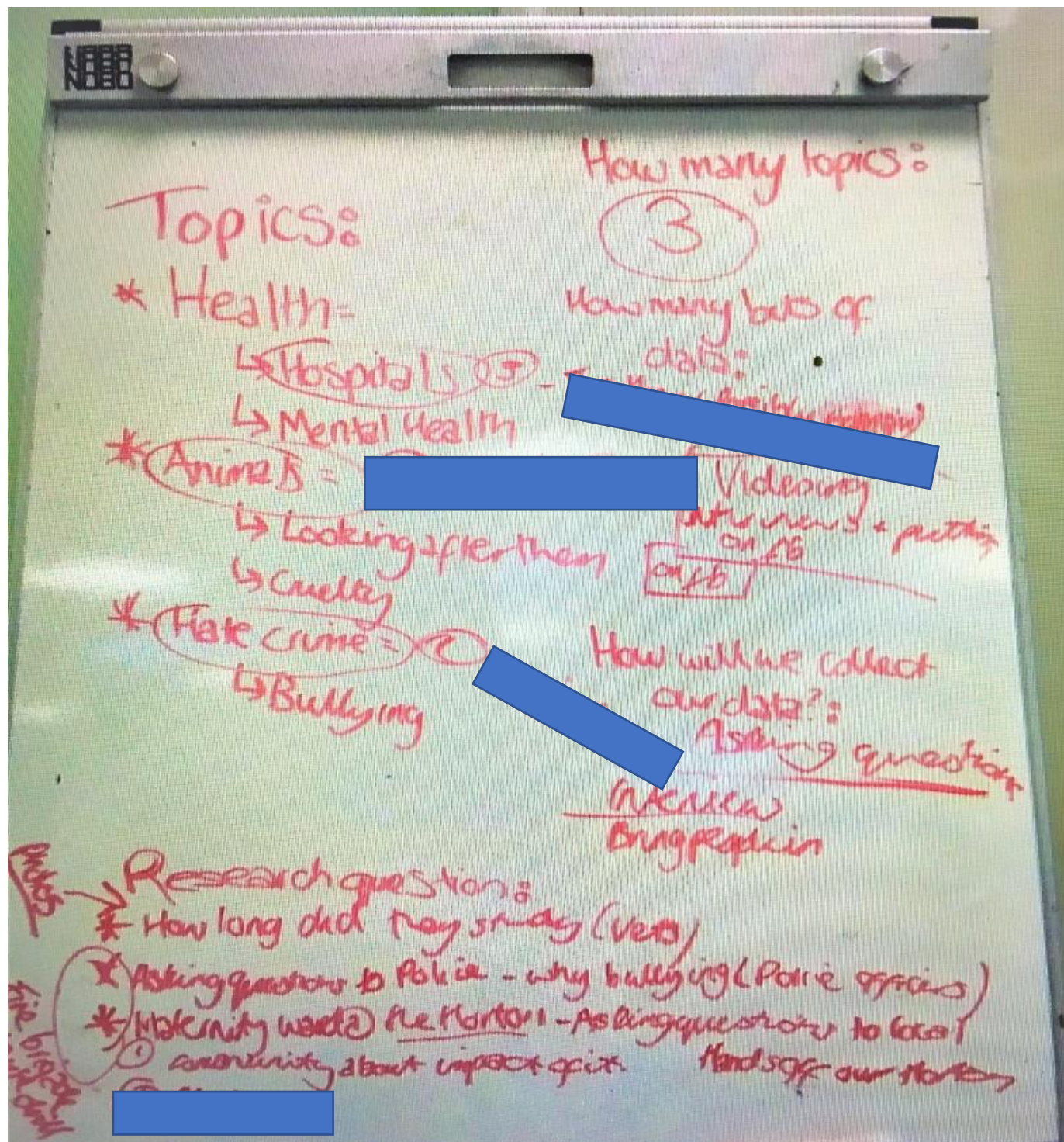
The second part of the session was structured to encourage the co-researchers to think about their research and begin to create their research questions. In Table 4 I outline my original plan for the session.

When showing the co-researchers the nQuire platform, I faced technological issues. The meetings of the self-advocacy group take place in a community building with no wireless internet. Access to the internet is a key consideration I would highlight moving forward with research within a group setting. In this case, we were able to gain internet access successfully as I had planned alternative access to ensure any technological issues could be overcome.

The nQuire platform includes a number of pre-loaded missions. In Session 4 we completed the breakfast survey. The co-researchers chose to engage with this survey verbally, with one person within the group reading out the questions and the others answering them. The co-researchers still seemed to be less engaged with the activity than some of the more creative activities we had done in previous sessions. They much preferred engaging in conversations surrounding the survey questions. However, they were able to link the nQuire activity to research when discussing potential research options in the second half of the session (Figure 7).

Whilst I structured this part of the session, the co-researchers chose the different topics of project and ways to conduct the research (Figure 7). This focused on different researchers perceived skills and offered an opportunity for the co-researchers to explore their capacity in this area. For example, P3 highlighted that their role (chairperson) within the group showed their capacity to talk to people and therefore they discussed wanting to conduct interviews. This displayed the co-researcher's abilities to understand their personal capacities.

Figure 7 - Co-researchers initial planning (Boxes added for anonymity)



This approach to inclusive research is based on previous research. In a project by CEPF (Central England People First) and Walmsley (2014), the people with learning disabilities worked alongside non-disabled researchers to conduct their own research. This included initiating the topic choices and conducting the data collection. However, in a review by

Strnadova et al. (2016), it is highlighted that the non-disabled researchers could also be involved in these activities at the behest of the CEPF team. This collaborative approach to research design reflects the approach used within this project. Whilst I, as a non-disabled researcher, structured the sessions, the co-researchers had control to change this. This facilitated approach to research design links to upstream engagement (Wilsdon and Willis, 2004), and the move within the scientific community for a more adaptive approach to research design (Chapter 2.4.1). Furthermore, the structure was put in place as a supportive tool to enable the co-researchers a safe space in which to explore new research skills.

Figure 7 conveys how the co-researchers were able to engage in this task and showed a clear understanding of the different parts of the research process.

4.3.3 Phase 2, Session 5: Research Plan

Session 5 was focused on planning for role delegation. Table 8 outlines the original plan for the session.

The first half of the session was focused on the co-researchers sharing what was done last session with those who had not been in attendance and agreeing on research topics. The co-researchers who had not attended the previous session wanted to introduce their own research topics. After we had discussed all of the potential research topics, we discussed the necessity to narrow this down due to the vast amount of time that would be needed to conduct all of them. I suggested focusing on two research topics, due to the size of the group which the co-researchers agreed with. To decide on our two research topics, the group decided that voting was the best option. Our vote concluded with two topic suggestions: looking after pets, and the local bus service. After this we focused on creating detailed research plans. To ensure the co-researchers were able to do this, I created a planning document prior to the session (Figure 8).

This planning document was introduced as a capacity building tool. It explained the different phases needed for research design and allowed the co-researchers to plan in more detail, supported by a trained researcher. I decided to create the document (Figure 8) in order to help structure the co-researcher's decision making. In previous sessions, the majority of the co-researchers had identified that they had not been involved in the planning of a research project before. Those that had, had only minimal experience and were not confident in their skills. Therefore, the production of the planning document was necessary to provide a

structure from which the co-researchers could work independently. Whilst this helped the co-researchers, they still required some support to stay on track and complete the sheets. Because of this, we only managed to fill in the sheet regarding one of the research topics which focused on pets and asking vets questions focused on how to look after them.

Figure 8 - Research planning document (for co-researchers)

Our research question is: _____

Our research team:

<u>Name</u>	<u>Role within the group e.g interviewer</u>

How we are doing our research:

Interviews

Survey

Group discussion

Other



Our participants are: _____

We will get in contact with them by: _____

Questions we want to ask them:

- 1
- 2
- 3
- 4
- 5
- 6
- 7
- 8
- 9
- 10



What do we need for our data collection e.g cameras, voice recorders:



The other topic was not completed as the co-researcher who was leading that group stopped coming to sessions due to personal reasons. None of the other co-researchers wanted to continue without them.

4.3.4 Phase 2, Session 6: Research plan and surveys

Session 6 was focused on putting the detailed plan into action.

The planning from Session 5 informed Session 6. The co-researchers decided that the best form of data collection for the pets topic was to send surveys to vets to explore common issues that the pet owners within the group had had with their pets. This meant we required a platform that could easily support this. I offered the co-researchers two websites that I knew of that could host surveys. The first was the Open University's nQuire platform (Figure 8) and the other was 'Survey Monkey', another platform that is supported by the Open University. The group chose to use 'Survey Monkey', as they did not enjoy using the nQuire platform. As we decided to not use nQuire for our data collection, it was not feasible to use it for the rest of the study. The platform was therefore dropped from the project.

In the previous session, two of the co-researchers had suggested they would do some research prior to our survey. This was to take the form of a literature review, looking at current literature online and in books which had information regarding the questions the co-researchers had posed. One of these co-researchers never returned to the group (personal reasons) and the other found they didn't have time to conduct this. However, it's important to note the co-researchers' understanding of the research design process and the importance of undertaking research prior to the investigation.

Prior to the session closing, the co-researchers wrote an email that we would send out with the link to our survey. The co-researchers made the decision to have me contact vets using the co-researchers email and ask them about filling in the survey as that was a job they did not want to do.

Session 6 allowed for some of the co-researchers to experience how to prepare for data collection. Furthermore, it allowed them to show their technical capacities and identified who would take on the role of leader within the group. I will discuss this in more detail in Chapters 5 & 6.

4.3.5 Phase 2, Sessions 7-10: Data analysis

Sessions 7 to 10 focused on different aspects of data analysis.

Session 7 introduced the co-researchers to analysis, framed through two games in order to create a fun space in which to develop our analysis skills. The first was a categorising game to show the co-researchers different ways that we can group data. Prior to the session I prepared some categories for discussion (Table 10). If people were part of that category, they were to put their hands on their head, if people weren't a part of that category you clapped your hands. The purpose of this game was to demonstrate categorisation through coding, whilst creating a fun, inclusive atmosphere for everyone involved.

The second game invited the co-researchers to work with photographs, treating them as data. They were then asked to work in pairs to find different ways to categorise these. This was then repeated with the same photographs. This task was aimed at getting the co-researchers to code data. Furthermore, the aim was to encourage the co-researchers to think about the different ways in which data can be interpreted and to justify those decisions.

We concluded the session by discussing how we could use these skills to analyse our own data. The co-researchers decided to print off the textual responses and use highlighters to look for themes within the data.

Session 8 was structured to allow the co-researchers to begin their analysis in groups with support from both myself and P11, the MLMC support worker. This enabled the co-researchers to explore their data and try out analysis in a supportive environment. An influence on the approach to this part of the research was a study conducted by Tuffrey-Wijne & Butler (2010), in which Butler one of the researchers with learning disabilities, was invited to help with the data analysis. Below is a quote from Butler where they describe the initial process the meetings went through:

“Then, in one of the advisory group meetings, Irene said ‘I need someone to help me with these stories.’ It was called analysis. So, me and Jane put our hands up. When I read the stories, Irene asked me to re-word it and make sense of it. She wanted to know what kind of things struck me on the page, because she needed another person’s reaction, to see if it was the same as how she or Jane might have read it. To see what were the most important bits.”

In the quote above, Butler reflects on their introduction to data analysis. By asking Butler to re-word the data, Tuffrey-Wijne was enabling them to highlight the key points within the text.

I chose to use this approach within this project. The group was split into two and were given the same two questions to look at. We then fed back and discussed our analysis and what we had found. This allowed for the co-researchers to see how people can interpret data differently and come to an overall conclusion.

The two groups took different approaches to their analysis. One group chose to focus on similarities within the data, highlighting what the group interpreted to be key points and finding what can be described as themes. The other group chose to use the data as discussion points, using the answers to the questions to begin their own discussions and create themes this way.

Similar to the session discussed in the previous Section, Session 9 was structured in order to allow the co-researchers to explore their capacity regarding data analysis in a supportive environment (Table 12). In this session, My Life My Choice had scheduled training for the co-researchers based around travelling. This had a large impact on our research as it meant there was significantly less time to focus on our data analysis. I was informed of this prior to the session, so had time to adapt any plans we had before the session meaning the group still managed to complete the analysis and raised some interesting points about the data. The co-researchers identified how many of the answers were contradictory and made the data confusing. This, the group decided, meant that the questions warranted further investigation using online sources. Furthermore, the co-researchers identified how many of the answers were not accessible if the contradictory nature and complex language used made it harder for the co-researchers to understand without support. This prompted the co-researchers to discuss how we might need to interpret the data in our write up to make it more accessible. In turn, this then planned the next session which was to focus on writing up our findings into an easy read format and conducting further research into the questions with contradictory answers. I will discuss this in more detail in the next Section of this chapter.

Session 10 was focused on completing data collection, analysis and write up (Table 13).

The session was largely led by the co-researchers, demonstrating increasing confidence in conducting research. The co-researchers decided to split into two groups, one led by P4 that focused on researching into the questions needing more clarification, and one that was led by P3 and P6 that focused on interpreting the analysis into an easy read format.

Again, the co-researchers were unable to complete the work needed in the time slot of the session. However, the co-researchers did identify the need to complete this next session and discussed how they could continue the work and potentially finish the write up. This displayed a greater awareness of project management, and an understanding of the importance of completing their work. This was decided in the final discussion of the session where we shared what we had done. I chose to do this separate from the plan so that all the co-researchers involved could understand what was required of them in the next session.

4.3.6 Session 11: Completion

The final session of Phase 2 (Table 14) was aimed at completion. All outstanding work was completed putting our analysis into an easy read format and finally create our output in the form of a leaflet (Appendix A).

It is important to note here that one co-researcher withdrew their consent to be recorded at the beginning of this session. This co-researcher also chose to not partake in any of the research related activities in the session. As per our agreement, this was accepted without question. Keeping to our agreement ensured that the co-researchers could be confident that their choices would not be judged and would at all times be respected.

The group split into two, I suggested that P4 concentrate on the extra research as they had led this last time whilst others focused on inputting our data into a leaflet format. Prior to that we needed to pick a leaflet, which was an activity led by P4.

When splitting the groups up it was evident that P4 was the only one truly confident with using computers, however, P6 and P3 supported one another to type in the analysis.

P4 and I finished collecting the extra research necessary and then put all the information into an easy read format. P4 then worked with P8 to teach them how to type on a laptop, finishing off the typing themselves.

Whilst we did get all the information onto a laptop in this session, we failed in entering it into the leaflet format. We then discussed how we could go forward with this with P11 suggesting that I visit a local community hub where most of the co-researchers attend on a weekly basis. This was agreed as the next step to ensure our output was completed in time for the final research session.

4.3.7 Summary of Phase 2 (Sessions 4-11)

The second phase of this project focused on detailed planning, creating a supported space for co-researchers to design a citizen science project, and putting their research design into practice. This phase of the project required a much more reflexive approach, as the co-researchers began to take control. Throughout the course of the second phase, the co-researchers learnt and then practiced new skills building their capacity to conduct research. Between each session, this meant that as a researcher I had to reflect on how much support the co-researchers would need in the next session. Furthermore, during each session I would need to make judgements as to when to provide support and when to withdraw. This reflexive process was constant throughout this project and enabled the co-researchers to identify their own capacities. Between both myself and P11, we were able to focus on building different capacities within the sessions to enable each co-researcher to contribute to the project in ways that they felt comfortable with.

One key reflection from this phase of the project, is that whilst working within an already established group has its advantages, it can also have its disadvantages. In the setting of this project (the My Life My Choice Banbury Group), there were occasionally other charity matters which demanded large amounts of the time during the sessions. As these were not planned into the original research design, they impacted on the time frame of the project and could often challenge the power within the group.

4.4 Phase 3, Sessions 12 to 13: Evaluating our capacity

Planning for Phase 3 coincided with news of Covid-19. The UK went into lockdown (23rd March 2020). Following this social distancing measures were required and working/studying from home was encouraged. As a result, I revised the approach for Phase 3 as a significant aspect of the planning for Phase 3 required face-to-face contact with my co-researchers.

The pandemic meant I had to adapt my approach using online creative, inclusive methods. I identified four possible options from the literature:

1. Phone interviews employing a biographic narrative interpretive approach (Bolton et al. 2005) by asking the individual co-researchers to tell me their story of the research.
2. Interviews using artefacts as prompts, e.g. by - sending photographs of the artefacts they created and ask them to talk about them.
3. 30 second review of the project asking co-researchers to send me a short-recorded review of the project.
4. Creative writing asking co-researchers to produce a piece of writing in whatever format they want talking about their experience of the project.

Each method offered an opportunity for reflection. I decided that options 2, 3 and 4 would rely too much on external forces, such as postal services. Furthermore, some of the co-researchers did not have access to technology and struggled with writing which would exclude them from participating in the task. Phone interviews offered the greatest flexibility for the greatest number of co-researchers; therefore, this method was selected.

In this section I will discuss the interview process and the data collected. Next, I will discuss my experiences as an inclusive researcher during this new process of generating data. Finally, I will summarise this final section of the project and the impact it had on the research, and its ability to answer the research questions proposed in chapter one of this thesis. First, I introduce the original plans for Phase 3 (Tables 15 and 16).

Table 15 – Phase 3, Session 12

Session #12	Phase 3: Session 12 Sharing findings
Roles	<p>JC and co-researchers – They will be creating their own research plans and will be running group discussions.</p> <p>MLMC staff/support workers – Can either choose to support participants or join in the activities themselves</p>
Activities	<p>How do we share information (e.g. findings from research)? 45 mins</p> <ol style="list-style-type: none"> 1) Photography – A collection of photos to answer this question. Firstly, how you share news, followed by how we think researchers share news – think about different methods for different audiences 2) Or, sharing a news article to camera – about how to share information 3) Later in the session we will exhibit these photos. Each person will provide a brief explanation of their photos (verbally or written) <p>Exhibition: In this session we will exhibit our photos (JC will have computer set up) Each person will have their description prepared and we will visit each ‘exhibition’ separately 30 mins</p> <p>Reflection space: 30 mins during first exercise</p> <ul style="list-style-type: none"> • Invite participants to discuss one or more of the items they’ve produced • What can they do now that they couldn’t do before? • What would they like to do differently? • What advice do they have to support other researchers?
Data collection & types of data collected	<p>Photography – supported by recordings of the discussion which follows</p> <p>Reflections/pictures</p> <p>JC Reflective journals – post session JC will reflect and evaluate how the session went from her perspective.</p> <p>Photographs/short videos will be taken during the session to support JC reflective journals</p> <p>Transcription from reflection space dialogue</p>
Outputs	<p>Informed consent</p> <p>Data on understanding of the importance of sharing findings</p> <p>Data on capacity to exhibit and explain findings</p>
Research Question	<p>RQ. What support do people with learning disabilities require regarding their capacity to engage with citizen science?</p> <p>RQb. Does a structured approach to capacity building support people with learning disabilities in their engagement with the research processes?</p> <p>RQc. Do methods derived from inclusive research support engagement for people with learning disabilities with citizen science?</p>

Table 16 – Phase 3, Session 13

Session #13	Phase 3: Session 13 Capacity
Roles	JC and co-researchers – They will be creating their own research plans and will be running group discussions. MLMC staff/support workers – Can either choose to support participants or join in the activities themselves
Activities	<p>What is capacity?</p> <ul style="list-style-type: none"> • Tableaux – in pairs make a tableaux (a frozen picture with you as the actor) showing what you think capacity is <ul style="list-style-type: none"> ○ Each pair will show their tableaux and the group will say what they think it is, after which the pair will say what the tableaux is showing • After this, individually, draw a picture about what you think capacity is • In a group – show our pictures and describe what they mean <p>Identity boxes 30 mins</p> <ul style="list-style-type: none"> ○ Make a new or update previous identity box, showing your identity as a researcher <p>Group discussion 15 mins</p> <p>How have we changed as researchers over the course of this project?</p>
Data collection & types of data collected	<p>Photographs of the tableaux's</p> <p>Artefacts – pictures</p> <p>Recordings of the explanations of the pictures</p> <p>Recordings of the discussions about the tableaux's</p> <p>Artefacts – identity boxes</p> <p>Recordings of the discussion that follows Reflections/pictures</p> <p>JC Reflective journals – post session JC will reflect and evaluate how the session went from her perspective.</p> <p>Photographs taken and recordings of the descriptions given relating to eat picture</p> <p>Photographs/short videos will be taken during the session to support JC reflective journals</p>
Outputs	<p>Informed Consent</p> <p>Data on how people with LD perceive capacity</p>
Research Question	<p>RQ. What support do people with learning disabilities require regarding capacity to engage with citizen science?</p> <p>RQa. How do people with learning disabilities understand research as a process that underpins citizen science?</p> <p>RQc. Do methods derived from inclusive research support engagement for people with learning disabilities with citizen science?</p>

4.4.1 Interviews

Five of eleven co-researchers agreed to be interviewed (P3, P4, P6, P8 and P9). We arranged to conduct semi-structured phone interviews, following a short protocol (Figure 9).

Figure 9 - Interview Protocol

Interview protocol –

- Informal, each participant will be asked to discuss their experience of the research freely

Opening statements:

1. Reinforce that this is informal, it is just a chat about their experience of the previous few weeks
2. Do they have any questions?
3. Remind them that it will be audio recorded and ask them about their consent

Key questions to be asked:

1. Invite participants to discuss what they thought about the study
 - a. What was there favourite part?
 - b. What did they enjoy the least?
 - c. What would they like to do again?
2. What can they do now that they couldn't do before? **(RQ1b)**
 - a. How does that make them feel?
 - b. Why couldn't they do it before?
3. What would they like to do differently? **(RQ1)**
 - a. Why?
4. What advice do they have to support other researchers? **(RQ1)**

Cohen et al. (2000) highlight how semi-structured interviews use prompts and probes to frame any prepared questions. In the interviews conducted in this project, the questions were used as prompts to encourage the co-researchers to reflect on their practice within the project. I created these as through my experiences with the co-researchers, I had found the co-researchers often reacted better when they were prompted with questions during discussions.

Each interview informed my approach with the next, therefore I had presented some of the findings here to explain the adaptations made in future interviews. My first interview was with P4, and it was during this interview that I realised some of the additional complexities of the COVID-19 situation for

my co-researchers. Without the face-to-face contact it was hard to understand their emotions and to react in an appropriate manner to these. In other contexts, this issue could be solved with the introduction of video conferencing software. However, with most of my co-researchers struggling with technological literacy this was not an option and therefore created a barrier.

P4 would only answer questions and needed to be prompted to talk. Furthermore, this co-researcher spent most of the conversation reflecting on their current situation in relation to Covid-19, rather than the project. Anticipating this might be the case, I ensured that we had an amount of time before the interview began to discuss any issues the co-researchers might be having. Whilst the aim of this was to give the co-researchers a chance to talk about their issues outside of a recorded conversation, it also provided a second purpose in allowing for a more conversational structure to naturally occur prior to the interview. Whilst in principle this was a good idea, I found that this approach prompted the co-researchers to focus on these issues which would then become a recurring theme throughout our conversation. The remainder of the interview was recorded, transcribed and included in the data analysis process.

P6 was the second interviewee. Whilst this co-researcher did focus on their current situation, they were also able to relate this to some of the work we had done during the face-to-face sessions. Principally, this was the potential to do some form of research with the NHS as was proposed by both P6 and P2 in the first phase of the project (Chapter 4). Prior to the interview I organised a time with P6 that suited them and wouldn't clash with any other engagements they might have had. Yet, near the end of the interview P6 declared that their lunch was ready so they would have to leave. This is another issue I experienced with remote data collection. In particular, with people who may not have control over when certain daily activities happen, such as those residing in supported living. This issue occurred again during my interviews with P8 and P9 who live together in supported living. Their support workers were with them during the conversations and proved to be a large distraction. They were aware of the research, as they had been provided with information sheets (Appendix E) prior to the study, however consent was not requested and any conversations with them was not included in the data. Furthermore, both P8 and P9 finished the conversations early. Both co-researchers required more prompting and needed a lot of reminding as to what we had done in the face-to-face sessions.

P3 was the final interviewee, and whilst P3 did discuss the current situation, it was clear the most important thing for them at that time was loneliness. They were missing the group and the structure of the meetings which took over most of their answers to the questions I posed.

Through my prior knowledge of my co-researchers and the relationships we had created over the year spent together I was able to create a level of free-flowing conversation. This allowed a space for the co-researchers to lead the conversation should they wish. It also allowed a space in which I could collect the data I needed whilst still being able to support the co-researchers through what is a particularly difficult time in their lives.

4.4.2 My experience

Reed (2016) highlights how as a researcher, “if you want to be good at knowledge exchange, then you need to take time to reflect on your activities” (p.59). Whilst I reflected on my activities as a researcher throughout the project, the final phase and the Covid-19 pandemic created a unique opportunity for me to reflect on “the me-search within re-search” (Pam Burnard, as quoted in Kara, 2015: p.71), and how the project had concluded.

There were two aims to these interviews. The first, was to collect data similar to the data I had planned to collect in my final face-to-face session with the co-researchers. Secondly, a more personal aim, was to find out how the co-researchers were dealing with the challenges of COVID. This, I argue, is a large part of being an inclusive researcher. Through the equality of power within the research, you build relationships with your co-researchers not only on a personal level, but also through the shared responsibility for the research you are conducting. We were all invested in this project.

P3 highlighted the importance of the social nature of this research and discussed how they missed working with the group. P6 spoke about how we had worked together as a team and how this was key to our research. P4 discussed the leaflet we were supposed to work on together, and how they were upset that this wasn't going to happen right now. All these data illustrate just how important an emotional connection between a research team is within this form of research.

In our interviews, we discussed how the co-researchers could stay in contact with friends and activities they could do to stay busy. At the time of the interviews, My Life My Choice were offering a phone buddy scheme where people were matched to ensure they had someone to talk to on the phone. I offered to become P3's phone buddy for a short while to provide them with a weekly opportunity to talk to someone.

This has affected me as a researcher. Whilst I know that this thesis will be submitted for examination, the change of circumstances has delayed the sharing of findings with the co-researchers. Once I am able to see my co-researchers again, I will visit them again and share the findings.

4.4.3 Discussion of Phase 3

Prior to the coronavirus pandemic, Phase 3 sessions were aimed at capturing the co-researchers' understanding of their capacities and creating a space in which they could self-evaluate these. By using a creative methodology, I had hoped to create an environment in which the co-researchers could be honest about their opinions to inform future research in this area.

After the pandemic hit, this was no longer an option. Kara (2015) states that the process of conducting an interview is creative, due to the relationship between interviewer and interviewee which creates meaning within the data (p.82). Whilst I did experience a form of this in these interviews, I also found the process much harder due to the lack of face-to-face connection.

Whilst the interview had a more conversational style, it felt more one sided, with me in charge. The only time in which the co-researchers showed they had any power within the conversation was when they would cut off the call before I had finished the conversation. Whilst this is important to note, it was also only a small part of the interview itself and therefore does not mean that the method overall was exclusive in its nature. Furthermore, the interviews had to be planned and conducted in a short amount of time under a great deal of stress. If more time for planning had been available, I believe they could have been developed to be more inclusive in their style. Planning and reflecting are key within inclusive research, as they allow the researcher to consider different scenarios and allow for greater flexibility in practice.

These interviews provided data that conveys the co-researcher's enjoyment of the project. Furthermore, it clarifies reason for enjoyment and, in turn, why the co-researchers engaged with the research helping to advise the theme of capacity which I will discuss in more detail in the upcoming chapter. The interviews also provided the co-researchers with the opportunity to provide advice to others who might wish to undertake this form of research. This data also helped to inform the theme of support which I will discuss in the upcoming chapters.

Part Three – ‘Give it a go’: Supporting Capacity Building

Chapter 5: Findings – Capacity

5.1 Introduction

As previously discussed (Chapter 3.5), data were initially categorised into two themes: capacity and support (Table 7). The data collected within this project consisted of written observations, creative artefacts created by the co-researchers, transcriptions of discussions and interviews. Each session had a selection of these and meant there was a need to analyse across different forms of data.

In this thesis I use the term capacity to refer to the different forms of engagement displayed by the co-researchers (Table 17). Furthermore, it refers to the skills the co-researchers display and those which they struggle with. I will structure this chapter by looking at each theme independently, followed by a detailed discussion of the overall findings within this chapter.

Table 17 - Capacity

Themes	Sub themes	
Capacity – The co-researcher’s abilities to engage in the project. Some of these they brought with them, others they developed over the course of the project	Engagement – the ways in which the co-researchers participated/or didn’t in the study	Fully engaged
		Distraction/being off task
		Interest in the task
		Understanding of the task
	Ability to recall – capacity to remember previous work	
	Advocacy – co-researchers speaking for others	
	Agency – taking the lead	
	Intrapersonal – co-researcher’s sense of self	Disabled identity
		Non-disabled identity
	Literacy – an understanding and knowledge of skills	Scientific literacy
		Inquiry/research literacy
		Reading and writing
		Emotional literacy
	Political – showing awareness of local and larger issues	
	Prior experience and knowledge – To inform discussions and descriptions	
	Self-advocacy – ways in which the co-researchers spoke up for themselves and their community	

Some of the sub-themes discussed within this chapter have been broken down even further as displayed in Table 17. Those sub-themes which stand alone, as the data did not suggest they needed to be broken down further, are highlighted in the table by the grey boxes next to the sub-theme title.

For each theme and sub-theme, I will discuss the different data found within them, with the aim of producing answers to the research questions (Chapter 1.1.3). Within this chapter I will display quotes from the data in italics to define them from the other text. Individual contributions from co-researchers are marked as P1, P2, etc. My contributions are marked as JC; the MLMC support worker is marked as P11.

5.2 Engagement

The first sub-theme I will discuss in this chapter is engagement. When coding this sub-theme, I was looking for any data that related to the way in which co-researchers did or did not engage. These examples provide evidence for different ways in which people with learning disabilities engage with both citizen science and, more broadly, research. During the analysis I coded four headings; fully engaged, distraction, interest in the task and understanding of the task. The first two of these discuss the different levels at which the co-researchers engaged and look at what specifically may have affected their engagement. The second two of these headings look at reasons for the co-researcher's engagement, or lack of. First, I will look at the heading of fully engaged.

5.2.1 Fully engaged

In this heading I aim to look at how the sessions encouraged the co-researcher's engagement. There were three key factors that I identified within the data that impacted on the co-researcher's engagement:

1. Links to topics of personal relevance
2. Enjoyment of the task
3. Decision making opportunities

The co-researchers appeared to engage with the project most when they could find links to topics of a personal relevance to them. Whilst this is not a massive revelation (Chapter 2.2.1), it is important to note that by encouraging the co-researchers to research on topics with relevance to them (Irwin, 1995), they were then able to engage with tasks that they perhaps may not have done previously. This links to the sub-theme discussed in Section 5.2.2 of distraction. Often the co-researchers would be distracted

by events happening in their personal lives or issues they were facing. By being able to link citizen science to these, the co-researchers had a higher level of engagement. One key example of this was the collages, where the co-researchers were encouraged to describe what research meant to them in a collage. Below are two examples Figure 10:

Figure 10 - Co-researcher's collages



Each of these collages linked to a personal issue that the co-researchers had experience of. By linking their ideas about research to these, the co-researchers were able to show what they defined as research; identifying problems that need addressing (inquiry) and raising awareness of the issues (dissemination).

This links into the second factor that encouraged engagement from the co-researchers. By enjoying the task at hand, the co-researchers were then more likely to engage. This is where an inclusive approach benefits citizen science. By allowing the co-researchers to lead the tasks they are engaging in, one is more likely to gain a higher engagement rate through their enjoyment. In this project, many of the co-researchers enjoyed taking part in the creative tasks.

JC – What, what do you reckon you enjoyed the most if you had to pick one thing that you enjoyed doing the most?

P8 – I'm trying to think

JC – That's alright, you take your time

P8 – Uhh, uhh, I think the box. I think it was the I think it was the box’

(Transcription_P8_Interview)

‘JC – So if you had to pick one bit what would be your favourite bit?’

P6 – My favourite bit I think was when we did the shoeboxes

JC – The identity boxes

P6 – Yeah you know yeah, the identity boxes yeah

JC – What was your favourite, why did you enjoy that?

P6 – Because umm it meant that I could sort of uhh choose quite a lot of different things to put into the identity box of what I used to of what my favourite things were sort of thing’

(Transcription_P6_Interview)

This view was reflected in almost all the phone interviews, apart from P9 who identified that they enjoyed the photography the most.

During the creative tasks there was little distraction, bar P9 who would routinely disturb the group to focus on their photography. This conveys that the creative activities were an important part of this project, and by using them at the beginning of the research we were able to create a space where the co-researchers felt comfortable to engage.

Furthermore, in this project I found that some co-researchers felt more comfortable engaging in the project in their own time and space. For example, P7 decided to work on their identity box at home, turning it into a book. By allowing co-researchers to work in ways that they were comfortable with, and being reflexive to their needs and requirements, more co-researchers were able to engage in the tasks. The first time this was experienced in the project was in Session 2 when P8 requested to take their identity box home to work on in their own time. Often during the sessions, P8 would be more interested in reading their newspaper than engaging in the group activities. By allowing the co-researchers the space and time to engage on their own, they were able to participate in the tasks.

The co-researchers on this project were often more engaged in a task when they were involved in the decision making. The sessions focusing on topic choice allowed the co-researchers to explore their personal vs. shared interests and begin to think creatively about ways of researching into them. This engaged more co-researchers and those who perhaps had not engaged in other activities in the project.

'This session was incredibly productive for the group. Many of the co-researchers were ones who may not often engage in discussions, but this time they did. This gave me a much more positive feeling.'

(JC_Fieldnotes_Session_4)

By offering greater power to the co-researchers and letting them lead the narrative of the research, they were able to take control and engage at a higher level in the activities. Furthermore, when able to make the decisions, the co-researchers were able to steer the research onto topics that were of interest to them and their community. The higher levels of engagement also showed an increased feeling of confidence with the co-researchers. The familiarity of certain tasks helped their engagement, and the lack of a need to build capacity gave the co-researchers more confidence in their skills. In addition to this, by engaging with familiar tasks as a group we were building rapport with one another and gaining confidence in working together.

5.2.2 Distraction

Distraction within this project was key to understanding why co-researchers did not engage. Through this heading we can see why co-researchers were distracted and how these barriers can be adjusted to ensure the learning-disabled community's engagement in citizen science.

There were four different things that distracted the co-researchers from their engagement.

1. Personal lives
2. Technology
3. Routine
4. Lack of interest in the task

Firstly, the topic of personal lives refers to how the co-researchers would distract both themselves and the rest of the group by talking about their personal issues or their emotions. Often this would be through linking to the project, then encouraging the discussion to go off topic.

'The group seemed to have had a particularly difficult month also affected the topics of discussion for the study.'

(JC_Fieldnotes_Session_2)

More often than not, these distractions would last throughout the activity or session affecting the co-researcher's ability to engage. This was conveyed in the final interviews conducted for the project

whereby the co-researchers would often reflect on the current pandemic whilst referring, loosely, to the research.

JC – Yeah do you enjoy doing arts and crafts then?

P4 – Yeah

JC – What sorts of arts and crafts do you enjoy doing?

P4 – Umm well I'm learning how to draw at the moment I'm using YoutubeTM to learn to draw umm I like colouring umm like cutting things out

JC – And why do you think I know this sounds like a really big question but why do you reckon you enjoy doing that? Do you enjoy doing that more than talking or?

P4 – Occupying my health (discusses mental health) it stops me from getting bored'

(Transcription_P4_Interview)

Whilst personal issues were a key distraction and would often overtake the whole session, the co-researchers would also use other aspects of their personal lives as a distraction from the activities.

'P8 – I'm going to see Mrs Browns Boys

P7 – You're going to see Mrs Brown

P8 – I'm going to see the stage show

P7 – Oh the stage show

JC – Guys'

(Transcription_Session_3_Group_Discussion)

Even though the sessions would include allotted time to discuss our personal lives at the beginning of the session, and any news we wanted to share with the group, these conversations would often spill out into the rest of the session.

Whilst these conversations would often distract the group, they would also create interesting discussions and the co-researchers could often find a link to a part of the research project.

'P4 - basically like my mum when she was in hospital they were really good in the hospital they don't normally allow people in the bit where they're waiting when they coming round with the station (removed for anonymity) they let her they let me into the room so that was really nice'

(Transcription_Session_2)

In the above quote, P4 is discussing how they define a citizen. By referring to the experience they had when their mother was in hospital, P4 described citizens as people such as nurses and doctors. This conveys how not all distractions have negative consequences. Sometimes, such as in the case above, distractions can provide key links and easy ways to convey meaning.

During the final set of interviews, the co-researcher's personal experiences played a big role in distracting them from the conversations.

'P3 – Yeah when's it gonna be finished then?

JC – Yeah, we don't know do we it's a bit of an unknown at the moment

P3 – They say it's gonna be the last one they said it's gonna be 10 more days innit

JC – I don't think they're really sure at the moment it's all just a seeing what happens

P3 – I just want it to be finished now so we can go back

JC – Yeah I know I know [P3] I'm feeling the same'

(Interview_P3)

This occurred in each of the interviews, and whilst was a distraction from the data collection, also highlighted the importance of being with the co-researchers in person. Prior to the interviews, I believed that the one-to-one nature of the interviews would lessen the ability for distractions. Yet, the isolation that the Covid-19 pandemic brought for many people meant that the co-researchers were often more interested in chatting.

Technology was also often a distraction. For one co-researcher, they were more interested in taking photos and looking at them than partaking in the task at hand.

'P9 - I'd like my picture taken please

JC - We can do that

P9 - With P3'

(Transcription_Session_10)

'P9 focused on the photographs they had taken from the previous session, asking me several times if they could take them home. This continued throughout the session, even when I had confirmed that they could take them home.'

(JC_Fieldnotes_Session_2)

This started in the second session when I introduced a camera for P9 to use as they had discussed how they did not want to take part in the exercises. Whilst this was aimed at providing P9 with a different form of engagement, it became a regular distraction whereby they would focus on the camera and photographs and their wish to take them home. This created an interesting issue where the tool for engagement became a distraction from engagement.

Another time when technology became a distraction was when I introduced the group to the citizen science platform nQuire. When setting up for the exercise I realised that the tablets I had brought in weren't working correctly which caused distraction for the group and broke our engagement with the exercise. It was difficult to regain this engagement after this as the quotation below conveys.

'P9 – Can we take the photos

JC – Not on the tablets I'll have to bring them in for you. So, you two what have you two?

P9 – Can I have a drink in a minute. I'm a bit thirsty

JC – OK

P9 – P11 I'm thirsty

P11 – Alright I'm gonna get the kettle on in a minute

P6 – I'll, I'll go do that P11

JC – That's OK

P11 – Hang on you need to be doing this

P6 – But I'll just

P11 – Can you just fill this bit in

P6 – OK

P11 – So just sit down a sec

P6 – Sorry.

(Transcription_Session_4)

This quote highlights how the technology, and failings of it, was the tool used here for distraction. By attempting to continue through this distraction the activity felt forced and lost its inclusive nature.

The routines of the group were also a cause for distraction. The self-advocacy sessions follow a set structure which has been in place for many years. The co-researchers were very used to these and would often be distracted by the next part of the structure. For example, the co-researchers were frequently distracted by an upcoming tea and coffee break and would talk about this and prepare for this rather than engaging in the task at hand. This identified how my introduction into the group, and the new routines that were introduced were disruptive. I was encroaching on their space and time, and their established ways of working. Yet, once rapport had been built and we had, as a group, agreed on new ways of working the productivity followed. This highlights how it is key for researchers working with the learning-disabled community, to accept that disruption will be present until new ways of working together are established.

This also links into the final topic of distraction, lack of interest in the task. If co-researchers were not interested in partaking in the task we were currently doing, they would fall back into routines. One co-researcher (P8) often focused on reading their newspaper, something which was a key part of their routine in these sessions.

Whilst these distractions would halt the process of the project, it's important to frame them as a positive. By understanding how co-researchers become distracted and by allowing space for this, I was then able to structure future sessions to include ways to bring these distractions into the sessions. Furthermore, the data from this project suggests that by encouraging the co-researchers to stay on task and not be distracted, not only did I lose the inclusive nature of the project, but the engagement of the co-researchers was often lost to the distraction. Furthermore, it's important to note that when entering into a pre-established group, a researcher is bound to be an initial distraction. Over the course of the project, I became less of a distraction and more a part of the group. This was, in part, due to adapting my methods to fit with into their context but also due to time. This is key for researchers to remember when conducting research such as this project, when analysing their data.

5.2.3 Interest in the task

As discussed in the previous two headings, the co-researcher's interest in the task was key to their levels of engagement. There were two key factors that impacted on the co-researcher's interest:

1. Personal Interests

2. Decision Making

Firstly, the co-researchers often showed more of an interest in an activity if it had some relevance to them personally. This was clearly shown by P9 as they did not engage in the citizen science project because they didn't have pets. Whilst it is not always possible to ensure that everyone has a personal stake in a citizen science project, researchers can ensure that co-researchers have opportunities to explore other forms of engagement that do reflect their personal interests e.g. photography for P9. Furthermore, by understanding the reasons behind P9's lack of engagement, i.e. no personal relevance, we can better understand the ways in which we can engage the learning-disabled community in citizen science studies.

Secondly, as discussed above, the co-researchers were more likely to engage in the activities if they were able to have some form of ownership over it. This was evident in Session 10, where the co-researchers began to complete their analysis and any further research:

'We worked well as a group, with me purely being there to prompt. The co-researchers displayed research skills and made me feel more like a team member than a leader.'

(JC_Session_10_Observation)

By creating an environment where everyone in the group had equal standing, the co-researchers were able to take over the decision making and were therefore more likely to engage. Furthermore, by allowing a space for group decision making, I was also allowing a space for the co-researchers to begin discussions. These discussions often framed the co-researcher's engagement and would be key to keep the project going.

5.2.4 Understanding of the task

One key factor in the co-researcher's engagement in this project was their understanding of the tasks. One barrier to this was the co-researchers perceived lack of confidence in their research skills. When asked about who they would want to conduct the research into their topic of 'bullying' P2 suggested that '*other people*' should do it as '*I wouldn't know what to look for*' (Transcription_Session_1_P2).

In order to overcome this, I delivered some research training as a key intervention to build capacity, reintroducing scaffolding for a period around a specific task. Furthermore, by moulding the training sessions to activities and topics the co-researchers could relate to, this furthered their understanding and made it easier for them to apply their skills.

'P6 – I had I had I had an idea

JC – Yeah

P6 – I would actually like to because of the umm because of the because of the hospital because of because umm the (local hospital) been in the news quite a lot recently I would like to sort of take the you know sort of do a bit of something to do with that I think'

(Transcription_Session_4)

The quote above shows how by linking research literacy to something the co-researchers had personally experienced, they were able to engage with the activity which in this case was identifying topics for research.

5.2.5 Summary on engagement

The theme of engagement looks at how and why the co-researchers did or did not engage in this project. Through the analysis of the data I discovered there were four sub-themes; distraction, fully engaged, interest in the task and understanding of the task. These four sub-themes each share commonalities which I argue are the important takeaways from this data analysis.

Firstly, the co-researchers in this project conveyed the importance of personal relevance for their engagement. In his generative text *Citizen Science* Irwin (1995) identifies the “need for and relevance of science and technology within everyday life” (p.34), which was reflected within this study. Whilst co-researchers would engage when there was no or limited link to their personal interests, there was a higher level of engagement when these links were present. Furthermore, the co-researchers were more likely to react in a positive manner to the tasks if they could explore topics and interests which linked to their personal lives. On the other hand, these could also create a distraction for the co-researchers occasionally taking the discussions off topic. However, this is not always a negative thing as this promotes a safe environment in which co-researchers can discuss topics and occasionally prompts further ideas related to the project.

The second key point from this project is that by offering opportunities for the co-researchers to partake in the decision-making they are more likely to engage in the project. This occurred through the recognition of and adaptation to the “real or perceived power imbalances” (Ellis, 2018: p.461) within the group. The transfer of control was a natural process which was facilitated through understanding and acknowledging the “different types of knowledge and skills” (Bigby et al., 2014: p.62) within the

group. By providing opportunities for co-researchers to demonstrate ownership over the project, alongside the researcher, the co-researchers are then encouraged to engage in the project. My role within these sessions initially disrupted the co-researchers and their established routines. However, over the course of the project, as the confidence of the co-researchers grew and we established new ways of working together my role became less disruptive and more a part of the group dynamic.

Thirdly, a key factor for engagement is enjoyment. This is a factor largely absent from the current citizen science literature, which focuses on the motivations for initial participation. One key motivation identified by Curtis (2015(a)) for sustaining participation is the opportunity to “make a contribution”. The link between enjoyment and Curtis’ motivation is that the co-researchers made contributions to the study when they enjoyed participating in the task. Co-researchers were more likely to not engage in a task if they took no enjoyment from it. In the interviews conducted at the end of the project, all the co-researchers involved mentioned how they enjoyed the creative activities within the sessions. These were the sessions with the highest level of engagement and least distraction.

Finally, a key part of engagement is the use of technology. Much of citizen science is done these days using technology, identified by Holliman and Curtis (2015). Yet, for many of the co-researchers in this group the use of technology created a barrier to their engagement. Whilst we cannot generalise for the entire learning-disabled population or for all uses of technology, we can assume that this will be the case for others and if so, one of the challenges for future work is whether this barrier can be removed. Furthermore, if it can be removed can citizen science succeed without technology, or can technologies be designed for different communities to promote inclusion?

These four messages from this theme teach us as researchers how best to support the learning-disabled community in their engagement with citizen science. By using an inclusive approach and allowing them to lead the narrative of the citizen science project to focus on topics that have a personal relevance and that the co-researchers enjoy, they are more likely to engage. Equally, by relying solely on technology to do citizen science we may be excluding a large part of this community. I will discuss this in more detail in the final chapter of this thesis.

By using an inclusive approach to citizen science, the co-researchers were able to lead the sessions and make decisions that suited them and how they preferred to engage. This relates to research question RQc (Chapter 1.1.3); Do methods derived from inclusive research support engagement for people with learning disabilities with citizen science? Through careful facilitation, the inclusive methods applied to these sessions created a group environment whereby the co-researchers could explore their personal

interests, make their own decisions, experiment with technology and then enjoy the research. By using these methods, I was able to support the co-researchers as they explored these in a safe space without judgement and in their own time. This is what I argue is key to support engagement for people with learning disabilities with citizen science.

5.3 Ability to recall

The sub-theme of ‘ability to recall’ is based on the co-researcher’s capacity to remember and discuss what they had done in previous sessions. It aims to identify what, within these sessions, may have supported the co-researcher’s capacity to recall. One defining feature of the data under this sub-theme is that different co-researchers recalled different parts of the project helping with the groupwork aspect as different people contributed to the collective conversation in recall. For many, this was based on their enjoyment of the different tasks. For example, in the final interviews of the study, P4 was asked what they would like to do again from the study. They recalled the collages and the other arts and crafts exercises.

‘P4 – Collage

JC – The collage what did you enjoy the most about doing the collage?

P4 – Well cutting things out about animals about cats and dogs and I love doing that sort of thing because it’s like arts and crafty bits’

(Transcription_Interviews_P4)

Whilst the co-researcher’s ability to recall differed, each co-researcher was able to recall a part of the research. Some focused on the creative aspects of the project:

‘JC – Yes we can definitely do a book thing, but we need to

P3 – Like a box thing, we did that box

JC – Oh the box thing

P3 – Put our pictures in it

JC – Yes so we’ll come back to those again another time but to analyse the data’

(Transcription_Session_7)

Others focused on the research and research topics that the co-researchers enjoyed being a part of:

'P4 - We were writing up what, what says well what you did was write up some of the questions the questions that weren't answered we researched the internet'

(Transcription_Session_11)

When conducting the analysis of the citizen science data, the co-researchers who had been in attendance in the previous training session were able to recall the methods used and use

JC – So they're asking us questions, like I've been doing a bit. So, in these sessions what've I been doing with you guys. Whilst you've been making your identity boxes what's one of the things I was doing. Can you remember?

P9 – Photographs

JC – What about what I've left on the table today?

P3 – A video camera

JC – A video camera ooh

P9 – A video camera

P8 – A laptop

P9 – A laptop

P5 – An audio cassette

JC – Yes exactly so I was recording what you were saying as well

(Transcription_Session_4)

This conveys the importance of using an inclusive approach combined with research training to offer the support for co-researchers to learn and then put into practice research approaches. Even with a month in between sessions, the co-researchers were able to remember the methods they had learnt and practice them with their own data. This shows that, with relevant scaffolding and support, it is possible to build a level of capacity to engage in citizen science and research more broadly, including studies over a longer time frame.

The co-researcher's ability to recall displays their understanding of the project as a part of the research process. I argue that this shows how an inclusive and creative approach to citizen science enables people with learning disabilities to engage and understand the research process. Furthermore, it

provides a supportive environment in which this community can learn about the research process and practice methods.

5.4 Advocacy

The co-researchers in this project, showed the capacity to not only advocate for themselves, but to advocate for other communities. This was most evident in the collage yourself activity (Section 3.3.1) when the co-researchers were encouraged to collage what research means to them. In these collages, the co-researchers discussed research that would help, stop and improve issues affecting not only them but other community groups as well.

'P1 - so yeah we need to go to more hospitals more learning because I was in hospital um even a couple of girls next to me cause they were in the same ward as me even they said we need more help'

(Transcription_Session_1_P1)

'P2 - a lot of us get bullied and a lot of children that get bullied go missing and it's a shame

JC - it is it is so what we have got here

P2 - elderly, frail, child

JC - frail so who's the frail

P2 - the elderly people'

(Transcription_Session_1_P2)

Through the identification of shared experiences, the co-researchers were able to find links to other communities and discuss the possibility of helping these groups through their research. This capacity to advocate for others displays another potential motivation to engage people with learning disabilities in citizen science, by linking the impact of research to their own communities' issues.

In Section 2.2.2 I discussed the different motivations for people to engage in citizen science projects. Here, I've identified how personal relevance was key to the co-researcher's participation. Yet it's important to note how the co-researchers used their personal motivations to also influence their altruistic motivations (Batson et al. 2002) to help other communities. This identifies how motivations, as they are described in the literature (Section 2.2.2), may not always be so clean cut. People may have multiple different reasons for engaging with projects or may begin participating for one reason and continue for another. The co-researcher's capacity to advocate highlights this by showing how people can have multiple reasons behind their motivation to engage.

5.5 Agency

One of the aims of this research was to identify the capacity of the co-researchers to engage in citizen science. Furthermore, I wanted to identify what forms of support, if any, that the co-researchers required in order to engage. The sub-theme of agency is used to highlight the different ways in which the co-researchers showed their capacity to take the lead within the project.

Firstly, the co-researchers showed how they were comfortable in making decisions as a group.

'The first decision they made was how to split the whole group. They decided to split it into three smaller groups by a majority vote'

(JC_ Fieldnotes_Session_4)

Whilst these conveyed a level of agency, it would be wrong to say that this group decision making was not framed by either myself or P11. In the quote above, the co-researchers are making a decision, however, this was after a question was asked as to how they would like to work as a group with myself and P11 providing the co-researchers with the options.

'P6 – Umm I was gonna say radio show

JC – Radio show, what go on the radio and see if we can tell people about our survey. What's another really easy, sorry I didn't mean to just

P9 – Ohh newspaper

P4 – Magazines articles

P9 – Ohh I can't hold this

P6 – Banbury Guardian

JC – What's another really easy way of contacting lots of people? What are lots of people on these days?

P4 – Mobile

(Unconsenting participant)

P4 – Facebook

JC – Facebook

(Unconsenting participant)

P4 – Cus I'm on facebook

JC – So we can ring them up, see if we can put a?

(Unconsenting participant)

JC – Whatsapp, that's a good one as well. So, in fact I have already used Whatsapp and Facebook because the only ones who actually replied were three of my friends, ones a veterinary nurse, one's a vet and one is owns a cattery

(Unconsenting participant)

JC – So we were only directing vets, or do you think we should make it larger than vets or do we only want to focus so what's the main question [P4]?

P4 – About how to look after I dunno what we said in the survey I completely forgot what we said

JC – So the main question was how do you look after cats and dogs'

(Transcription_Session_7)

By providing options to the group they were then encouraged to make the larger decisions on how we worked as a team. Whilst the framing of the decision-making could be seen as a negative, it also provides a positive space in which to build confidence with this skill.

Another form of agency shown within this research project was the co-researchers wish to complete and continue work in their own time.

'P4, P8 and P7 had all worked at home regarding their identity boxes.'

(JC_Fieldnotes_Session_3)

By showing these different forms of agency we can identify that the co-researchers were capable of making decisions and leading their own objectives for the research. Yet, it is important to note that often these decisions were supported and at times framed through the involvement of either myself or P11. This, however, did create a good group dynamic and allowed for the co-researchers to explore agency in a safe supportive environment. The approach to facilitation within this project, focused on the introduction of support when needed and the withdrawal of it when it wasn't. By framing the decision-making process, both myself and P11 were supporting the co-researcher's capacity building

and not forcing them to make decisions they weren't comfortable making on their own. This was key to the co-researchers prolonged and fruitful engagement.

5.6 Intrapersonal

Selin et al. (2016) describe intrapersonal capacity as a “person’s sense of self and critical understanding of their own identity in relation to others” (p.637). Intrapersonal capacity is shown by the co-researchers in this project through the way in which they identify themselves in relation to others and how they see themselves, as opposed to what others see.

Under this sub-theme I categorised the data in two ways. The first was how the co-researchers identified with their non-disabled identity whilst the second focused on their identification with their disability. Both influence the choices made by the co-researchers and the ways in which they engaged with citizen science. By allowing space and time for the co-researchers to explore their identities independently and as a group, they were able to find commonalities and create a research project around this. Furthermore, by encouraging the co-researchers to think about their identities from the beginning of the research they were able to explore the development of a new part of their identity, citizen scientist.

5.6.1 Non-disabled identity

During the first phase of this project, the co-researchers were encouraged to evaluate their identities and their relationships to research. Figure 11 is a picture of one of the identity boxes created by P4.

This picture conveys different parts of this co-researcher’s identity:

1. ‘Girls just want to have fun’ – identifying their gender but also an aspect of their wishes in life through popular culture
2. ‘Confidence is a superpower’, ‘strength’ and ‘positive’ – identifying three key parts of their identity
3. ‘Tennis’, ‘pink’, ‘France’ and ‘baking’ – identifying things they enjoy doing or that they like.

These themes of likes and hobbies, and personality traits were found throughout the co-researcher’s identity boxes and the discussions we had around them. This conveys how the co-researchers understand their identity by what they see about themselves, not necessarily what others see of them.

Figure 11 - Identity Box



The co-researcher's capacity to define their identity, separate from their disability, enabled them to engage in research and discussions around research which potentially impacts other communities. Furthermore, the identity boxes influence how those around the co-researchers see them ensuring that they are viewed in ways that they relate to. This is an important dimension in group settings, making a cohesive working environment. This links back to Selin et al.'s (2016) description of intrapersonal capacity and the importance of empathising and connecting with others outside of your immediate communities.

5.6.2 Disabled identity

In Chapter 2.3.1 I discuss the literature around identity and labelling. Beart (2005) introduces the idea that the label of 'learning disabled' is not an identity used by much of the



learning-disabled community. This theory is reflected in the data collected within this project, where disability appeared to be less important than other factors of the co-researcher's identities.

In fact, during the project, learning disabilities were only mentioned twice by the co-researchers. The first time was by P1 during the collage yourself activity (see figure 13), when discussing what research meant to them.

'JC -So P1 what've you you've done more about help us what does that say?

P1 - help

JC - that says help citizen

P1 - yeah dementia patient

JC - ok oh so you've

P1 - it's like people who've got problems in their

heads and that and autism like I've got'

(Transcription_Session_2_P1)

Here we can see how P1 identifies their disability alongside people with dementia, finding connections between their identity and being a citizen in need of medical help.

The second time disability was mentioned within this project was by P6 when following on from a conversation about a famous comedian who had recently developed Parkinson's disease:

'P6 – I've not got much umm I just the reason why I put these in is because I love the colours of the of the sort of the tissue paper and that's what the reason why I put these in because I like things that are colourful and things so. Speaking about you know you guys were talking about what people have got well believe it or not I've got, I've, I've was born with a thing called and this is no joke I was actually born with a thing called Cerebral Palsy'

Prior to this, P6 was describing their identity box to the group in which they only placed things to represent their like of colourful things, not their disability. I argue that this shows how this co-researcher valued other parts of their personality such as things they liked, over their learning disability.

By understanding these two different layers to identity; disabled and non-disabled, and which is valued higher by the co-researchers we can better frame citizen science to motivate the engagement of the learning-disabled community. The intrapersonal capacities of the co-researchers highlight how they can link many parts of their identities to issues that could be of interest to the citizen science community. By creating this link, we are in a better position to support both the learning-disabled and research community in interacting and engaging with each other.

Furthermore, by identifying the level of intrapersonal capacity within the learning-disabled community, we can engage them in issues that are far more wide reaching than just their community.

5.7 Literacy

In Chapter 2, I discuss scientific literacy and its importance to citizen science. It is identified by many in the literature as a key motivation for a citizen's engagement in a citizen science project (Jennett et al. 2016; Land-Zastra et al. 2016; Jones et al. 2018; Curtis, 2015(b)).

In the discussion of the literature I argued that scientific literacy can exclude those who do not already possess these skills and interests. In this section of the thesis, I aim to discover if this was the case for these co-researchers.

In addition to scientific literacy, when analysing the data from this project I identified other forms of literacy displayed by the co-researchers. Here I define literacy as an understanding and knowledge of skills, e.g. reading and writing.

By identifying and discussing these, the aim is to understand what levels of support are required from the citizen science community to enable engagement of people with learning disabilities. As such, I will look at how these literacies developed throughout the project and whether the inclusive methods used enabled this.

5.7.1 Scientific literacy

My Masters project (Carr, 2018) identified how the term ‘science’ could be a barrier to the engagement of adults with learning disabilities in citizen science. In order to overcome this barrier, I used the ‘draw a scientist’ activity (Chambers, 1983) to encourage the co-researchers to develop a shared, and positive, understanding of science and scientists.

‘P6 - basically it's my well umm sort of brainstorm of what a scientist because sometimes scientists always do like brainstorming and coming up with new things and umm so sometimes like they always come up with new things and and things and so like a that's why so my that's like my sort of attempt at doing like a scientist sort of thing’

(Transcription_Session_2)

The co-researchers linked scientists to the ideas of brainstorming and creativity. At no point during these discussions did the co-researchers use negative language to describe scientists as they understood them. I did not ask them to define who they considered scientists (i.e., researchers, doctors or teachers), as we were developed a shared understanding of a scientist’s key qualities and not their occupation.

Furthermore, during the process of the project some of the co-researchers would use scientific and mathematic language to express their thoughts.

‘JC – Yeah so we can say that there are four people that have brown hair and then we can say that there are five people who don’ t have brown hair. So, what does that mean?’

P9 – I’ve got brown hair

P4 – It means four over five’

(Transcription_Session_7)

Their understanding of science and scientists led their citizen science project down the route of reproducing knowledge rather than producing new knowledge, i.e. collecting data from vets about how to look after pets. The importance of this, in this context, was that by conducting the research and gathering the information the co-researchers were then able to distribute this to their community in a format that would be much easier to understand (i.e. easy read). UKRI (2019) suggest in their 2019 Delivery Plan the focus of citizen science should be on engaging under-represented communities. By doing this the co-researchers aimed to use their skills to provide information to their community on a

topic which impacted them, looking after animals. This displays an understanding of science, and the fact that a scientific project does not always need to produce new knowledge. Instead a project can reproduce knowledge which is new to either the researchers themselves or the targeted audience.

5.7.2 Inquiry/Research literacy

In this thesis I use the terms inquiry/research literacy to discuss the co-researcher's understanding of how science works and is produced. During this project the co-researchers were introduced to research skills such as data collection and analysis through a capacity building programme (Chapter 4). For some, these were new skills whereas others already had experience and knowledge of these. As discussed in Chapter 6, the co-researchers were able to identify different levels of inquiry from local to national.

'JC - Oh wow so you've actually got something about the report ok

P2 - It's about the MP's

JC - Pardon

P2 - it's about the MP's

JC - oh OK

P2 - bullying things

JC - yeah

P2 - yeah

JC - ok and what's it so it's about the MPs and what do the MPs do, do you know

P2 - talking about bullying'

(Transcription_Session_1_P2)

This level of knowledge in the first session highlighted to me, as the external researcher, that the co-researchers were aware of research uses outside of a community context, i.e. political debates. Whilst this showed a level of inquiry literacy and understanding, the co-researcher in the quote above also identified their lack of confidence in inquiry.

'JC - ok so what you want to do research to do that or you want other people to do research to do it

P2 - other people

JC - other people not you yourself no ok

P2 - I wouldn't know what to look for (giggle)'

(Transcription_Session_1_P2)

This emphasised that, whilst the co-researchers may have had prior experience of inquiry, they themselves may not have been involved in the production of the research.

Another way in which the co-researchers displayed their inquiry and research literacy was through their identification of different data collection methods.

I next asked the co-researchers how they wanted to go about doing their research i.e. what sort of research methods did they want to use. P3 and P6 suggested bringing in the co-researchers to do interviews. This fitted all the other studies as well.

(JC_Fieldnotes_Session_4)

JC – So how are we going to find out this information?

P4 – On the internet

JC – On the internet so we're going to collect information on first aid on cats and dogs?

P4 – Yeah information yeah

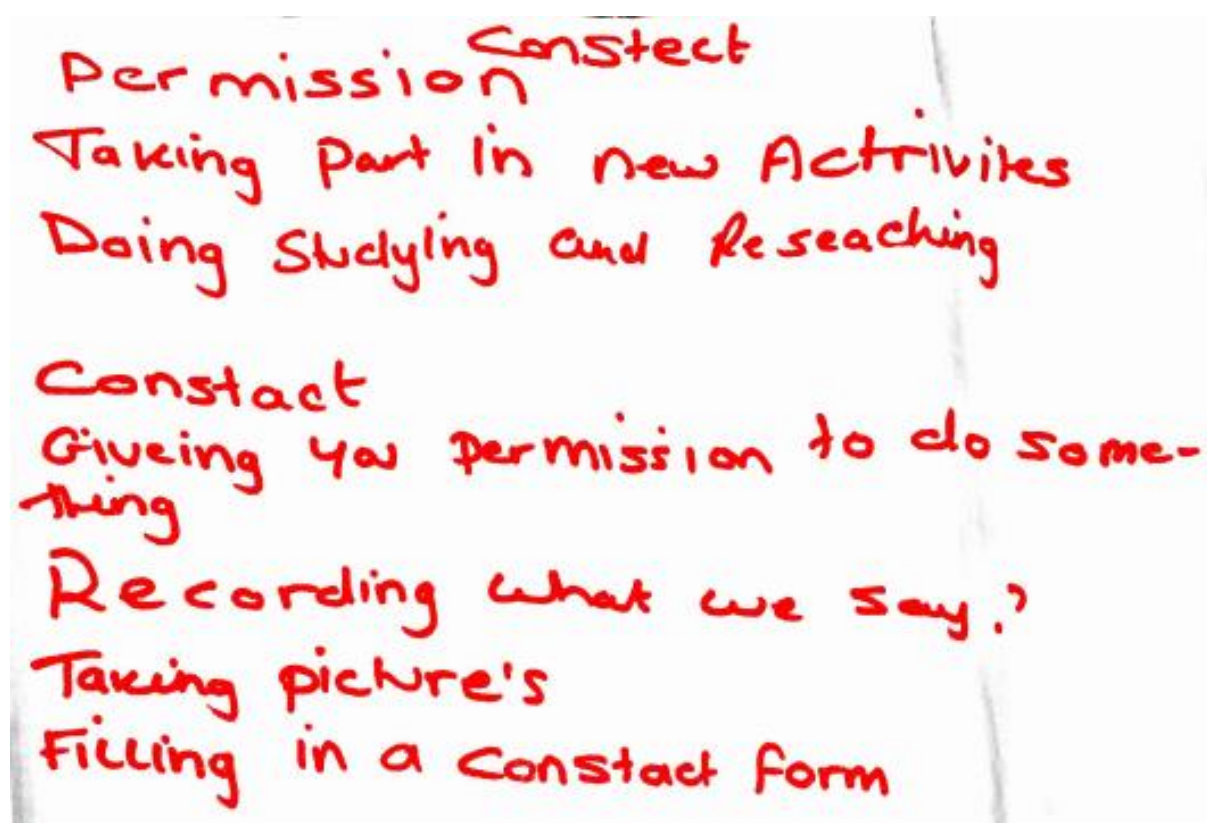
(Transcription_Session_5)

The co-researcher's identification and knowledge of data collection methods was evident throughout the sessions, with the co-researchers making their own decisions on how to collect the data for their research. This displays an understanding of a wide variety of different data collection methods.

Finally, the co-researchers displayed their inquiry and research literacy through their understanding of consent (see Figure 13).

Consent is an important part of research, especially when people are involved. The co-researchers were encouraged to consider consent and define what it means. The key term the co-researchers highlighted was 'permission'. This displays an understanding of the key terms related to inquiry and research and an understanding of the complexities involved in researching with people.

Figure 13 - Notes on consent



5.7.3 Reading and writing literacy

When engaging in a research project, there is often an element of reading or writing involved. This can be exclusionary for people who may lack these skills, or struggle with certain elements of them. For this group, there was an element of this with some of the co-researchers asking for help when it came to writing things down. Yet, within a group of just 11 co-researchers, there was often at least one person who could support this. By using inclusive research methods and creating an environment of equity the co-researchers were able to turn to one another for support instead of myself or P11.

One example of this was in Session 11 when the co-researchers were asked to use a computer to type up our findings:

'P4 wrote out the easy read versions of the other questions into another word document with P8. This was P8's first time using a computer and P4 helped them by showing them how to type. P4 also allowed P8 to type out one of the questions, showing them where the letters were and giving them verbal encouragement.'

(JC_Fieldnotes_Session_11)

The support provided by P4, who had experience of using computers, allowed for P8 to engage in the activity and take an active role in the creation of the findings. Furthermore, it allowed a co-researcher who had previously struggled with writing to learn a new skill and improve their writing literacy using technology.

By employing an inclusive research approach, not only were co-researchers able to engage in reading and writing in a supportive environment but they were also able to develop these skills and learn new ones.

5.7.4 Emotional literacy

The next form of literacy I will introduce is emotional literacy. The co-researchers of this project displayed two different types of emotional literacy. The first focused on their ability to understand the emotions of others within the group. During the discussion of different topics, co-researchers would occasionally be prompted to remember difficult experiences.

'P3 – My dog got bitten last time

P4 – Oh

JC – Well do you want to talk about that now?

P4 – You worrying about that?

JC – You wanna talk about, yeah? Do you want to tell us about it?'

(Transcription_Session_5)

Through recognising and reacting to this the co-researchers were able to create interesting and safe discussions. These were then used to influence the research.

'(P3 tells the group a distressing story about how their dog was bitten – not written here to protect anonymity)

P4 – Well I put on here how to look after cats and dogs plus how to do first aid on cats and dogs if they get bitten or if they’

(Transcription_Session_5)

By reacting in this manner, P4 is not only displaying emotional capacity but also an understanding in how to apply this to research.

The second way in which the co-researchers showed their emotional capacity was in showing empathy for those outside of their own community.

‘JC – So P6 quickly, coming back to you, talking about hospitals and the (local hospitals) what questions did you want like what do you wanna learn about the (local hospital)

P6 – Well basically, what I want what I because I think the way that that umm that the like sometimes the way that some of the uhh like peep like when people go from like one I think it’s bit crazy that when it comes to uhh like for instance uhh when like ladies have to go from one place to the other it’s a bit it’s what they call mad that they have to go from one place to another if you like’

(Transcription_Session_4)

Here, P6 is identifying the importance of a maternity ward to local pregnant women. This then prompted a discussion amongst the whole group about the potential danger that the closing down of this maternity ward could cause.

The co-researchers in this project used their emotional capacities to influence their research, in particular their topic choices. Emotional capacity, in the context of this project, did not need to be built. Yet, its relevance lies in the influence emotion has on every choice made within the project and on the co-researcher’s engagement. This, in turn, is relevant to future studies and is key for facilitators and researchers alike to acknowledge. By encouraging emotional literacy, personal motivation to engage can be fostered and long-term engagement more possible.

5.7.5 Summary

In Section 5.7 I have identified the different literacies displayed by the co-researchers. The importance of this is in by understanding the literacies held by these co-researchers we can aim to adapt citizen science to create a space in which to develop these.

The data presented above suggests that whilst the co-researchers of this study did display some of understanding of the research skills, the inclusive approach to research training enabled them to develop the different literacies needed to engage with citizen science. By following a distinct research process and allowing time for capacity building, the co-researchers were then able to engage and support one another at each stage.

Inclusive research accepts the fact that people come to the research with different levels of skills. Each co-researcher has something to offer the group environment. By using this approach and acknowledging that people have “different types of knowledge and skills” (Bigby et al., 2014: p.62), people are able to learn from and support one another. This is where citizen science can be developed, through the introduction of an inclusive approach to enable engagement with wider publics.

In this project, I have identified four types of literacies that impacted on the co-researcher’s capacity to engage in this research: scientific, inquiry, reading and writing, and emotional. For future research in this area, and future citizen science projects with the learning-disabled community to be successful, facilitators and researchers must acknowledge each of these literacies when planning their interventions. Whilst other participants or co-researchers may display other or different literacies, these four were identified as key to this project and therefore have been discussed in detail in the Section above.

5.8 Political capacity

Selin et al. (2016) describe political capacity as how “a person understands and can act upon political or public matters” (p.637). In Phase 1, Session 1, the co-researchers displayed their understanding of both political and public matters through their collages of what research meant to them. The topics they chose to represent in these collages all had personal relevance (Irwin, 1995) and a wider impact outside of their community:

1. Animal abuse and general care
2. Policing of hate crime/knife crime
3. Bullying
4. Hospitals

The co-researchers identified how these issues had an impact on the wider public, not just the learning-disabled community and showed a clear understanding of issues faced by their local community:

P1 - well the NHS I've uh I've been I was in hospital I ended up in hospital due to that broken leg of mine so there you go

JC - And what does that how does that relate to research for you what does that mean to you

P1 - well going by the conversation between me and my mum and a couple of others on the bus was we need more hospitals we need more nurses we need more what not cause the NHS is on the...decrease

(Transcription_Session_1_P1)

Here P1 identifies how they understand the issues facing the NHS currently, relating it to a time that they were in hospital and needed medical care. P4 also identified a public issue in their collage, by relating it to a personal experience:

P4 - Well on Saturday there was this dog rolling around. He had no lead no nothing. I went into the shop and said whose dog is this and he said it's mine. And he's still putting back where it was. I said it needs a lead. No, she don't she will stay. No, she didn't she just kept roaming. I was scared she was going to go in the road and hurt herself

P1 - you get some intolerant people in shops

(Transcription_Session_1_P4)

These two examples show how the co-researchers identify public issues through their personal connections and experiences with them.

During the interviews, P6 discussed the importance of the NHS during the recent pandemic linking it to a potential future research project by the group:

JC – Yeah so would you if you were to do some research again would you do it on one of on a topic that we discussed or what what would you?

P6 – Yes I would I would I'd definitely well I if I did it again and if I sort of, I'd probably my topic I'd probably go for would be the NHS

JC – Yeah that's quite important right now as well isn't it?

P6 – Yeah

JC – So what now that you've done all the research and you know you've done all that yourselves all you guys did it all completely on your own what do you feel that you can do now that before going through all this with me that you couldn't do before?

P6 – Well what I what I because like like you say with this coronavirus thing going on and stuff

JC – Yeah

P6 – And I because uhh they were saying they've been saying quite a lot of how how so many people are basically sort of dying from the coronavirus and stuff

JC – Yeah

P6 – I think it's made it a lot more sort of a lot more sort of umm uhh really important that that we I I've actually been the only thing that I I've been staying in most evenings and that to sort of keep myself safe anyway and also and and also but also I went out for a walk today just to and that but umm I think that if truth be told and the thing is that I don't want (removed for anonymity) to get poorly so that's why I I've find actually about I find the NHS thing quite important

(Interview_P6)

Here P6 displays an understanding of current political issues and can link it to their personal experiences. Also, by highlighting the potential for a future research project P6 shows a capacity to not only understand the political but to think critically about the issues.

Whilst the co-researchers displayed a clear understanding of public issues, only one participant identified an understanding of political matters, linking it to the public matter of local hospital closures:

'P6 – I would actually like to because of the umm because of the because of the hospital because of because umm the (local hospital) been in the news quite a lot recently I would like to sort of take the you know.. sort of do a bit of something to do with that I think

P6 - Cus there's apparently there's been like a there's like a protest at the minute about the (local hospital) I think

JC – oh about the maternity ward'

(Transcription_Session_4)

In the examples above, P6 has identified a local political issue relating to the closing down of the maternity ward. Furthermore, P6 conveyed their knowledge of the protests about the closure currently happening within the local community. This data provides a different insight into the political capacities of the co-researchers in this project. In the previous sessions we had discussed political

issues which had a personal connection to the co-researchers. Here, P6 identifies an issue with little relevance to either themselves or the rest of the co-researchers. Yet, it does have an impact on the wider local community.

The co-researchers of this project not only understood research through its aims, but also by the different levels of research (Figure 14).

Figure 14 - Co-researcher's levels of research



Personal – linking the research to a personal experience e.g. knife crime

Community – referring to an issue that has wider impact within a certain community e.g. hospitals – maternity wards

National – issues that are discussed at a national level e.g. bullying, and the policies that are made as a response to research

By identifying the co-researcher's capacity to understand political issues with direct impact on both themselves and the larger local community, we can better understand how to engage the learning-disabled community in citizen science. Through the inclusive methods used within this project, the co-researchers were able to discuss and create their own research. By setting their own agendas the co-researchers were able to explore political issues that interested them, rather than what others perceived to be important.

This is key for future researchers and facilitators working in this field, in that they must not make assumptions about a group's political capacity. Instead, by creating a supportive environment where

political views and opinions can be explored and developed this capacity can be built upon to create vital research into topics that impact specific communities.

5.9 Prior experience and knowledge

During the project, the co-researchers used their prior experience and knowledge of both research and local issues to influence the ways in which they engaged with citizen science. Firstly, I will discuss how their previous experiences impacted their topic choices and understanding of research. Next, I will look at the co-researcher's prior knowledge of certain topics and how this influenced their engagement.

As discussed previously in this chapter, the co-researchers framed their understanding of research through their previous experiences and issues of personal relevance to them. When the co-researchers could draw on prior experience and connect the research to their personal interests, they were more likely to engage with the project. Contrastingly, those without prior experience of the topic or a personal connection were less likely to be interested in engaging. By understanding this, we are able to look at the design of citizen science projects and introduce an inclusive aspect into the design process. By drawing on prior experience of communities, the engagement process can be more fruitful, and the research can have a larger impact.

Links can be made here to capacity building. In the first phase of the study the co-researchers identified their experiences and showed their knowledge on specific subjects. The key to this study was building on the co-researcher's "valuable insider" perspective (Nind, 2016: p.550) whilst still developing their capacities to become a researcher (Strnadova et.al, 2014: p.20). Early in the second phase of the project, the co-researchers of this project reflected on their previous experiences with research:

'JC – That's cool. So, what did you guys think research was before you did this?

P9 – I'm not sure

JC – You're not sure. P3 did you have any idea what research was before. Had you done any research or been part of any research?

P3 – P11?

P11 – Have we done research before. We've done bits around campaigning haven't we?

P3 – Oh yeah yeah

P11 – ‘Cus we talked about getting evidence remember that? We looked about yeah evidence for stuff. So, we’ve done some research around that and you guys have been involved in research because we did some stuff with HealthWatch remember that?’

P3 – Oh yeah

P9 – HealthWatch

P11 – Years ago

P3 – Eating innit

P11 – Yeah but we all looked at health checks for people with learning disabilities and we did some role play in the group

P6 – That’s one thing that sticks to mind

P9 – Role play’

(Transcription_Session_4)

The co-researchers were not able to recall the experiences by themselves, but by understanding what sorts of research the group have been involved in previously I was able to plan sessions to reflect on the skills they may have already developed. Furthermore, by understanding whether the co-researchers had any prior experience, I was also able to ensure the right level of research training was provided.

During the write up and analysis process of this project, the co-researchers were able to draw on their knowledge of the learning-disabled community to create a more accessible output:

‘On the second question (when to get pets neutered) one of the groups identified that the answers were contradictory. We then discussed what this means and how we would work out the correct answer.

There were more discussions about how the survey responses were not in an accessible language. This could need more investigation about whether this affects their ability to understand data without support’

(JC_Fieldnotes_Session_9)

In the fieldnotes quoted above I highlight how the responses not being in accessible language could cause a need for more support. Yet, the co-researchers were still able to engage with the data analysis

and complete this section of the research. Furthermore, this then encouraged the co-researchers to translate the findings into an easy read format. It is only through their distinct prior knowledge that this was recognised and acted upon.

This contribution to knowledge identifies how all communities have the capacity to influence many different topics through their prior experience and knowledge. Yet, it is key for researchers and facilitators looking to work in this field, to not make assumptions of knowledge and experience (Nind et al., 2015) but instead to focus on the building of capacities. In this project this was done by acknowledging the different experiences and knowledge of the co-researchers and building on these to create new experiences and knowledge. The key to this work, is the acknowledgement that everyone brings something different to the group, and that this in itself is important for the work.

5.10 Self-advocacy

In Chapter 6 of this thesis I will describe self-advocacy as when people with learning disabilities are in control of their lives and are making decisions which affect them and their community. I define it here as a form of capacity; learning to speak up for yourself and understanding the issues that affect your community. This is a skill which takes practice.

The group of co-researchers in this project were well-versed in self-advocacy having practiced it through their membership of My Life My Choice. They displayed their capacity to self-advocate through their agency in decision making and their ability to understand the issues facing the learning-disabled community:

'P1 - oh people like me people like me like we were saying earlier the help we need guidance we need the support we need for people like me who need help'

(Transcription_Session_2_P1)

Furthermore, some of the co-researchers of this project displayed knowledge of the importance that they were the ones to conduct the research.

'P1 - maybe a group of maybe a group of like we've had different people doing it but why don't a group of us do it then we could end up on Radio Horton and stuff like that'

(Transcription_Session_1_P1)

By using an inclusive approach to offer the co-researchers an opportunity to explore the ideas of conducting their own research, I was able to ensure their engagement in a citizen science project of their choosing.

Self-advocacy has the potential to play a large part in the engagement of people with learning disabilities in citizen science. By encouraging them to take charge of the entire research process, the co-researchers are able to lead the narrative and therefore control the engagement.

This contribution to knowledge highlights the importance of power balance within research. By creating an equitable research environment, the co-researchers of this project were able to take control of their own research process and build their different capacities also.

Walmsley & Johnson's (2003) principles for inclusive research state that "[research] should be collaborative, people with learning disability should be involved in the process of doing the research" and that "people with learning disability should be able to exercise some control over the process and the outcomes" (p.64). Both principles identify the importance of self-advocacy in research with people with learning disabilities. This data in this project highlights the importance of building capacity for this to enable an equitable research group and ensure the inclusion of currently excluded communities such as people with learning disabilities.

5.11 Discussion of Capacity

The theme of capacity has explored the different skills and experience which, in this study, the co-researchers displayed. The data discussed in this chapter, has identified barriers which affect the learning-disabled community and their opportunities to engage in citizen science

Throughout this chapter, I have identified the importance of personal relevance or motivation to the co-researcher's engagement. In Walmsley & Johnson's (2003) principles of inclusive research (Chapter 2.4.1) the idea of issue relevance was raised. Similarly, I have noted Irwin's (1995) discussion of the "need for relevance of science and technology within everyday life" (p.34). This highlights how both inclusive research and citizen science reflect the findings of this study and shows a clear link to build on when combining the two research approaches.

By adopting an inclusive approach to citizen science and allowing the co-researchers to lead the narrative of the research, I argue that we can engage the learning-disabled community in research with an impact on their community. The co-researchers identified in this study how research to them was

used to ‘help, stop and improve’ issues (see Chapter 4.2). By reflecting this in the planning process of citizen science we can better engage this community and offer them a space to use their voices for change.

In the analysis of the data of this study, I identified different barriers to the engagement of the co-researchers. Firstly, the ways in which the co-researchers were distracted from the study. Largely, these were based around issues in their personal lives which affected their ability to engage through a lack of focus on the task. Yet, by allowing space and time for this and by finding ways to link these to the activities, we were able to explore their issues through fruitful discussions. This highlights a key part of Tilly’s (2015) study, in which the co-researchers identified how the inclusive approach gave them the opportunity to have “a voice, identify social barriers in their lives and gave them support and confidence to action about them” (p.121). Through treating these ‘distractions’ as opportunities to identify social barriers, the co-researchers were able to further their research. Another potential barrier to engagement in this study, was the lack of literacies. Again, by creating time to allow for training and by adopting a group dynamic these barriers were often overcome. Through understanding the different skills within the group co-researchers were able to support one another and lead to a higher level of engagement.

The second capacity discussed in this chapter, was the co-researcher’s ability to recall. The data under this sub-theme highlighted how the co-researchers were able to recall certain aspects of the project, in particular activities which they had enjoyed. The contribution to knowledge from these findings is that by using activities that the co-researchers enjoyed, they developed an understanding of the research process therefore developing other vital capacities for engaging in citizen science.

The third form of capacity discussed in this chapter looked at the co-researcher’s ability to advocate for communities other than their own. The data highlighted how the co-researchers used their personal interests to influence their altruistic motivations for research, engaging with topics with a wider impact than just the learning-disabled community. The contribution to knowledge here is how science communicators and researchers alike, need to acknowledge the complex reasons behind people’s motivation to engage with citizen science projects. By encouraging different communities to engage and researching into topics with a wide impact, we can engage those currently under-represented communities in the citizen science discourse.

The next form of capacity discussed in this chapter highlighted the co-researcher’s ability to make decisions and lead the project. Largely these decisions were supported by a non-disabled researcher,

with either myself or P11 helping to structure the decision-making process. The sub-theme of agency contributes to knowledge by informing science communicators and researchers of the importance of building this capacity when working with the learning-disabled community. Agency can be built through reflexive facilitation, supporting when needed and removing this support when it isn't.

In this chapter I discussed the co-researcher's intrapersonal capacities, splitting this into two: disabled identity and non-disabled identity. The purpose of this was to better understand how the co-researchers understood their own identities, and how their understandings impacted on their engagement with the project. The findings highlighted how the co-researchers considered their non-disabled identity more important than their disabled identity. This contributes to the citizen science discourse by encouraging science communicators and researchers alike to consider the differences between intrapersonal capacities of different communities. Furthermore, by introducing activities that get co-researchers/participants to consider their identities at the beginning of a project, links can be made to potential citizen science projects encouraging engagement.

This chapter looked at the different literacies displayed by the co-researchers and their impact on engagement. Firstly, I discussed the co-researcher's scientific literacy highlighting how the co-researcher's shared understanding of science, led them to create a project which did not produce new knowledge but instead reproduced knowledge which was new to them. This is key for the citizen science discourse, as it encourages science communicators and researchers to consider how a project does not need to create new scientific knowledge, instead it can reproduce knowledge for new audiences. Secondly, I looked at the co-researcher's inquiry literacy. The data under this section highlighted how the co-researchers had a wide range of inquiry literacy, understanding key terms and displaying knowledge of the inquiry process. This identifies how it is not that research is exclusive to this community, but that the way facilitators and researchers approach working with the learning-disabled community that has resulted in their current under-representation. Next, I discussed the co-researcher's reading and writing literacy, highlighting the importance of an inclusive approach to this form of research. The co-researchers which lacked this capacity were supported by others in the group who were more capable. This identifies how support in capacity building doesn't need to come from only the non-disabled researcher, but also from the other members of the group. Finally, I discussed the co-researcher's capacity for emotional literacy. The impact of emotional literacy in citizen science, is in its influence on personal motivation. By encouraging emotional capacity within co-researchers/participants, science communicators and researchers can create more opportunities for engagement linking projects to communities' interests.

The next form of capacity discussed in this chapter was focused on the co-researchers' understanding of the political. The data identified in this sub-theme highlighted how facilitators and researchers need to avoid making assumptions about communities understanding of political issues, and instead use this capacity as a way of engaging currently under-represented communities in inquiry projects.

The data in this study, identified how the co-researchers drew on their prior knowledge and experience to influence not just their topic choice but also the way in which they approached research. I argue the importance of this is that the learning-disabled community have different lived experience to those from outside of the community. Nind (2017) identifies how inclusive research “represents [people with learning disabilities] lived experience” and “value[s] their different ways of knowing” (p.278). Through acknowledging this and treating those currently underrepresented communities as experts instead of amateurs, citizen science research can begin to engage a much wider base of publics.

The sub-theme of self-advocacy explored the co-researcher's ability to advocate for themselves and their community. The data under this heading highlighted how an inclusive approach to research (Walmsley & Johnson, 2003: p.64), encourages a more equitable environment in which to build this capacity ensuring the inclusion of under-represented communities such as people with learning disabilities.

The capacities of the co-researchers in this study have highlighted how the learning-disabled community are not only capable of engaging in citizen science research, but how they can provide a unique voice in the citizen science discourse. Through approaching barriers with an inclusive approach, we can aim to include this community better within research and respect their voices within the research community.

Chapter 6 – Support

6.1 Introduction

Chapter 6 explores the second key theme of the analysis: support. Through the theme of support, I will explore the different ways in which capacity was built with the co-researchers during their participation with this project. By understanding which processes and methods enabled meaningful participation, a key aim is to explore how to better prepare future citizen science organisers to engage with the learning-disabled community.

When analysing the data, I identified three sub-themes. Firstly, the sub-theme of facilitator looked at the role played by the non-disabled co-researcher (me, represented as JC, and the MLMC staff, represented as P11) and the support they were required to provide to enable engagement. Secondly, the sub-theme of co-researcher focuses largely on the group dynamic and how the co-researchers supported one another. Thirdly, the sub-theme of environment looks at the importance of the external factors within this project such as, the location and routines of the group and the part these played in supporting engagement.

In Table 8 I detail the different headings of the sub-themes and outline the different research questions addressed by each. These will be discussed in greater detail in the sections that follow.

Table 18 - Support

Themes	Sub themes	
Support – The different factors involved in providing support to the co-researchers to enable their engagement	Non-disabled researcher	Encouraging involvement of the co-researchers
		Finding links between ideas
		Personal support
		Prompting to focus
		Structuring
		Technical aspects of the task
	Co-researcher	Confidence
		Disability
		Helping others to engage
		Leading decision making
		Technical aspects of the task
	Environment	Location
		Number and nature of non-disabled researchers
		Routines

6.2 Non-disabled researcher

Walmsley (2004) identifies how the role of the non-disabled researcher is often mystified within the inclusive researcher literature. This thesis aims to provide a clear explanation of this role, and the importance of it for the co-researcher's engagement. The sub-theme of non-disabled researcher focuses on the different ways in which I and My Life My Choice staff supported the other co-researchers in the group. In this Section I will discuss the different approaches I took during the project, highlighting particular support by MLMC staff, and how these did or did not enable engagement from the co-researchers.

Strnadova et al. (2014) argue that the learning processes within capacity building programmes such as the one discussed in this thesis, should be two-way. This has long been the aim of public engagement, with the Wellcome Trust (2001) stating that “an ‘engagement model’ of science communication - a two-way dialogue between specialists and non-specialists - is more appropriate than the ‘deficit model’, which only gives information about science” (p.315). Whilst the co-researchers are learning new research skills, the non-disabled researchers are learning, “how to best support and assist their colleagues with intellectual disabilities” (p.16). The theme of ‘non-disabled researcher’ highlights how the non-disabled members of our research group (myself and P11) supported the co-researchers and documents the process of learning this.

When planning this project, my belief was that by allowing time for the co-researchers to learn about the different research skills, i.e. research planning, data collection and analysis, the level of support required from me would be gradually reduced, creating an environment where the co-researcher could “articulate their views “in their own ‘language’ and on their own terms”” (Durrell, 2016: p.2321). First, I will discuss how a large part of my role within the group was to ensure the involvement of the co-researchers within the project.

6.2.1 Ensuring the involvement of the co-researchers

When I began to plan this project, I knew I would have to be reflexive to the needs of the co-researchers. In order to do this, I allowed myself time before the project to start to get to know the co-researchers and build rapport. This time was not used to understand the different needs and skills of the co-researchers; however, a level of understanding was developed by observing their engagement in the MLMC sessions. The majority of the understanding of skills was developed during the sessions, and the reflexive approach applied allowed time for me to work with different co-researchers to learn about

their specific skills. It is key that when working with vulnerable and previously excluded groups, that a facilitator takes time to both build rapport and understand the support needs of the co-researchers/participants.

In the first session, P9 identified how developing an understanding of the co-researchers' needs was key to their engagement. P9 highlighted in this session how they did not want to partake in the exercises, instead they wanted to take photographs and develop their hobby of photography:

'P9 – refused to engage. Next session bring a camera as a back-up option. They can take photos of the other co-researchers engaging and show the story of our research'

(JC_Observation_Session_1)

Through talks with the co-researcher I was able to gain an understanding of what I could do to get them involved with the project in a way they would enjoy. For this co-researcher, that was photography.

Figure 15 - P9 Photography



For other co-researchers, encouraging their involvement meant giving them visual prompts which they could refer back to at any point which described keywords we were talking about during that particular session, e.g., citizen science, research, citizen.

As the project progressed, some of the co-researchers began to take control of the group by leading the decision making and supporting others within the group. Occasionally, this meant that others would get left behind; they were not included in the process. In order to reintroduce their involvement, I would ask other co-researchers to teach the ones who had less developed skills in that area of research:

'JC – P8 do you want to come round here then you can type in this one or do you want to sit next to P4 and P4 can teach you type? Do you want to sit where I'm sitting?'

P8 – Yes.'

(Transcription_Session_11)

By engaging other co-researchers in the process of including others, we were able to work more supportively as a group. Furthermore, it allowed me to adapt my role from 'facilitator' to 'co-researcher'. Bigby et al. (2014) identify how in inclusive research using collaborative groups, "researchers are not simply there to assist" (p.8). Instead, they should ideally become a part of the group. This was clear within our research, as I both assisted and contributed to our project.

Another very simple way in which I encouraged involvement and engagement from all the co-researchers was to find links between the different ideas they had:

'JC – There was something that she wanted to research into, which was, she wants to ask vets questions. And she wants to ask them about, 'how long did they study, how do you study animals?', and learning about the different breeds of dogs and cats. Do we think that's a topic that a group might be interested in?'

P9 – Yes

JC – Because I know there were some people like P4 was quite interested in animals wasn't she, would anyone else be interested in doing that?'

(Transcription_Session_4)

In the quote above, I was attempting to link ideas for a research topic. By doing this, I was able to ensure that the co-researchers were all able to explore their topics of interest in the planning process.

6.2.2 Structuring

When preparing for this project, I planned upstream for each session and validated that approach with the MLMC support worker (Chapter 4). By adopting an inclusive approach, I was aware that these plans would, in all likelihood, need to change to suit what the co-researchers wanted from the project. Yet, even when the plans needed to change, maintaining a clear structure to the sessions was still key. The co-researchers were used to routine (Section 6.4.3). In effect, the early sessions established a new form of structure. Whilst disruptive to a degree at first, this routine then became really important.

One way in which the sessions were structured in this project were by the resources both I and P11 created to support the co-researchers working. For example, in Session 4 without having prepared any resources in advance I made use of the break to create a quick structure for how we would plan our research (Figure 9). This enabled the co-researchers to plan their own research with very little support from myself or P11.

The aim of providing a structure to the project was to allow for the co-researchers to take as much or as little control in the project as they wished to. The co-researchers did take part in the decision making, yet as I identified in Section 5.5 the decisions made were often structured by either myself or P11:

JC – You should see mine, umm, so P4, what, what question, what is our big question for the cats and vets one?

P4 – Vets and cats

JC – But that's not a question

P4 – Oh question oh

JC – We need to come up with a question

P4 – Got to come up with a question, umm, how do we look after them?

(Transcription_Session_5)

Often in this project, my role was to ask the questions required to further the work. By taking on this role I was able to use my experience of a research to enable the co-researcher's experiences and knowledge of their community shine through.

6.2.3 Personal Support

In the routines of the My Life My Choice group, the members are offered the opportunity to discuss any news they want to share. This created a space where the co-researchers could share issues they were having in their lives at the time.

'The co-researchers were overall happier than normal, with some feeling negative in regard to life related issues'

(Observation_Session_4)

This is a key part of the role I played within the group. By being a person the co-researchers could turn to for personal support, alongside the MLMC support worker, I was able to build a rapport and create a safe space where no one would be judged.

6.2.4 Prompting to focus

When conducting the analysis of the data, the sub-theme of 'prompting to focus' was the most common within the data. It was a key part of my role within the group, bringing the group's attention back to the task they were completing at the time:

'JC - Ok and why does that mean research to you?

P3 - I don't know

JC - is it something personal?

P3 - yeah personal

JC - and is it something you want to research into is it something that you're just interested in?

P3 - Yeah hmm.'

(Transcription_Session_1_P3)

Often within the sessions this role was to ask probing questions to enable the co-researchers to continue focusing and to also progress their work. Other times, it was to bring attention to the time frame that the co-researchers were working in.

I explained to the group that we only had three more sessions left and we needed to get this project finished. I explained what we had left to do and asked how they might want to approach this session.

(JC_Observation_Session_10)

This was important to the role I played within the group as a co-researcher and a facilitator. It enabled me to encourage the group to build capacity with the aim of fulfilling their roles and complete their research.

I argue that this is where groupwork, rather than working independently, increased the engagement in this project. Using an inclusive approach, we were all able to use our own skills to complete the research. Furthermore, using my position as a more experienced researcher, I was able to adopt a role within the group that did not force my power and objectives upon them. Instead, I was able to encourage their work and direct their focus.

6.2.5 Technical aspects of the task

As discussed under the sub-heading of ‘co-researcher’, a key part of support within this project was helping the co-researchers with any technical aspects of the task. An example of this was in the first session, where the co-researchers were asked to read and fill in their consent forms:

‘I went to each participant and talked through the consent form, getting verbal agreements from the co-researchers as well as written.’

(Observation_Session_1)

The co-researchers displayed their understanding of consent through their discussion of the term. The most used phrase was ‘permission’ which conveyed their understanding of the idea that consent is permitted by a person. I ensured that the co-researchers equally understood that permission could be taken away if they wished.

Ensuring the co-researchers in this project gave informed consent was important to the ethics of this project. By allowing time and sitting down with each co-researcher individually I could ensure that they were able to give informed consent. Furthermore, it allowed for the co-researchers who may have struggled with reading and writing to still engage. This, I argue, could be a barrier to involvement of the learning-disabled community in citizen science research. Unless attempts are made to overcome the barriers to engagement created by a lack of reading or writing literacy, we cannot expect to gain consent, or indeed further engagement from people who may struggle with these skills.

6.2.6 Summary of non-disabled researcher

At the beginning of this section, I highlighted how Walmsley (2004) identified a need within the inclusive research literature to discuss the role of the non-disabled researcher. In Section 6.2, I have looked in detail at the role of the non-disabled researcher. A key part of this role was to ensure the co-researchers had every opportunity to engage, as they identified their own “support needs for participation” (Strnadova et al., 2014: p.16). Often this meant that the non-disabled researcher took on the role of bringing the rest of the group’s attention back to the task.

The non-disabled researcher role, as I have termed it in this thesis, is a key role within the group. As Walmsley (2004) identifies, “being explicit in accounts of the work...enables others to learn from experience” (p.68). I have described how the non-disabled researcher role was mainly technical and focus based. It took preparation, and reflection on the role to move from a ‘facilitator’ position of power, to be sharing the research with the co-researchers. Therefore, this thesis argues that to successfully produce inclusive citizen science, the non-disabled researchers must be prepared to adapt their approach and also respect not only the co-researchers but their own voice within the research.

6.3 Co-researcher

The sub-theme of co-researcher looks at the different ways in which the co-researchers of this project supported each other and the ways in which they displayed no need for support from the non-disabled co-researchers.

The data within this sub-theme details how the group dynamic played an important part in the co-researcher’s ability to be confident in their own capacities and support one another. I argue that by fostering an inclusive research approach and creating a space whereby all people within the project developed a shared understanding of equity, the co-researchers were able to explore their capacities in a collaborative manner, and not always seeking out support from elsewhere.

It is important to note, that as a self-advocacy group the co-researchers in this project were used to the idea of taking control and leading their own decisions. Yet, my observations prior to the project were that these were often structured and in part led by a non-disabled member of the My Life My Choice staff. The inclusive approach in this project allowed the co-researchers to explore self-advocacy and speaking up for themselves in a safe environment.

Over the course of the 12 sessions we spent together I observed the co-researchers building confidence and looking for support less and less. There was an obvious shift in power in the second and third phases of the study, as the co-researchers took control over the activities conducted. From this point onwards, the co-researchers began to grow in confidence and identified less of a need for support.

Frankena et al. (2018) identifies the different roles held by researchers with learning disabilities in inclusive research teams. These include: “advisor, career tiger, co-researcher, expert by experience, teacher and translator” (p.722). In this project the co-researchers identified with many of these roles, which I will discuss in more detail below.

To explore this sub-theme in detail I have split the data under six headings. The first of these which I will discuss here is the heading of ‘confidence’.

6.3.1 Confidence

In this thesis I will define the term ‘confidence’ as a display of belief in one’s capabilities, and a lack of need for support from others. In Frankena et al.’s (2018) discussion of roles, confidence is linked most closely to that of the “career tiger” which is categorised by the researcher’s ability to: handle new things, help others, communicate and identify their strengths and weaknesses. In the discussion that follows, I will highlight how the co-researcher’s confidence grew as they developed new skills, supported their fellow researchers, and communicated their needs and wants for the study.

Whilst research training was provided throughout the project, the transient nature of the co-researchers meant that not all of them were present during these sessions. One of the co-researchers for whom this was true was P2. In the first session of the project P2 attended and identified that they were not confident in conducting research, instead preferring ‘other people’ to do it on their behalf. When P2 re-joined the group in session nine, their lack of confidence in their skills was still evident:

JC – The actual analysis the going through it and picking out what was similar as opposed to the answers what did you think to that experience?

P2 – It was OK

JC – Yeah do you think you could do it again with something else?

P6 – Mhmm

JC – So say you could, ‘cus My Life My Choice do a lot of research stuff

P2 – I know, tell me about it I'm in the relationship stuff that's hard

(dissenting participant)

JC – And especially then I imagine in a lot of the stuff you do you've got to read like big reports and stuff and take in information from it so you're looking for kind of those snapshot things. So, I suppose you guys do it quite often actually

P2 – Yeah

JC – But do you think you could do that without any support or so like someone like me or P11?

P2 – No. '

(Transcription_Session_9)

P2 would turn to both myself and P11 (the other non-disabled co-researcher) for support during the project. Observations show that they often felt uncomfortable engaging in activities without us present. Yet, as we discuss in the quote above, this co-researcher had prior experience of research and frequently presented findings of this to groups of people with the learning-disabled community. Later in Session 9 we discussed this lack of confidence and found that for other co-researchers this had to do with a lack of prior knowledge or interest in the research topic. However, the topic of our research study had been decided by majority group decision meaning the minority who did not choose this topic did have less interest. Yet, this did not mean there was always a lack of confidence.

P1 in this project displayed their confidence in their decision-making skills from the second session, choosing to continue with the activity from the first session rather than start a new activity. During this study, P1 was the most outspoken and was aware of their capacities. Yet, they also displayed a willingness to learn during the discussions they took part in, asking questions and encouraging others to discuss their topics in more detail. They were absent for much of the latter stages of the project, but P1 did join one of the analysis sessions.

In this session P1, alongside two other co-researchers, decided to analyse the data given to them in a different way. P1 had already discussed their lack of interest in the research topic but engaged, unsupported, in the analysis activity. The difference between P2 and P1 is that P1 came to the project with more confidence in their skills. In the first session P1 declared that '*a group of us should go there even*' (Transcription_Session_1_P1), referring to people with learning disabilities going to research

into the topic they were collaging about. This displayed a level of confidence within their research skills, which P2 did not have.

These different levels of confidence show that within a project with multiple co-researchers, each person will bring different skills with them. P4, was very adept at using technology and was keen to be involved in any task where technology was used. P8 on the other hand had very limited knowledge of computer. By using an inclusive approach in this project, I was able to provide the co-researchers a safe space in which to explore their capacities and turn to others for support when they needed it. For example, in the final session P4 supported P8 as they tried to type on a computer for the first time.

P4 – So basically typing like a typewriter so H O W can you see it or not. How to feed a cat or dog

P8 – I can see it

P4 – H there

P8 – H

P4 – And then there you go do you know where an O is

P8 – There

P4 – No it's there, that's it W is that one W yep that's it space and then put to which is T O

(Transcription_Session_11)

By acknowledging P4's skills with technology and P8's lack of skills, we were able to provide a teaching opportunity for P4 and a learning opportunity for P8. This then boosted both co-researchers' confidence in different skills.

Kellett (2010) reflects on the 'children as researchers' literature, highlighting how "the experience of participating as active members is an empowering process that leads to a virtuous circle of increased confidence and self-esteem" (p.197). This is reflected in this project, where the co-researcher's confidence grew the more involved, they became in the research. The quote above is a key example of this, where P8 who had no confidence in technology was willing to try even though they had not engaged in much of the research process prior to this. This displays a growth in confidence to try new skills, where previously they had not been willing to do. The co-researcher's confidence with research skills grew throughout the process, as they tried and developed new skills. Furthermore, their confidence in working as a cohesive group developed over the course of the 11 sessions we worked together.

6.3.2 Renegotiating (Dis)Ability

One way in which the co-researcher's ability to engage without support was hindered was the language used within the survey responses. The co-researchers identified how the answers were often contradictory and not accessible in nature. This links closely to Frankena et al.'s (2018) definition of an expert by experience, as they identified what people with learning disabilities need to be able to engage with the research.

Walmsley (2004) argues that the role of the non-disabled researcher is "vital" to enabling people with learning disabilities "participation in research" (p.66). The inaccessibility of certain data sets, and subsequent adaptation to make it accessible, requires someone with this skill set. In this context, the co-researchers were able to adapt the data, with support, and therefore identifies how both the disabled and non-disabled researcher roles are key to a successful inclusive approach.

Yet, I argue that this could be avoided by structuring the data collection process in a way to provide only accessible data. For example, instead of using a survey the co-researchers could have engaged in interviews with their intended audience potentially making the answers more accessible to them. It's important to note however, that this could limit data collection in particular the amounts of data which is collected. The survey was chosen as the data collection method by the group after we had discussed different data collection methods. This was prompted by my suggestion of surveys and P7's questioning of whether interviews would be a viable data collection method. Furthermore, data collection could be arranged with people from the learning-disabled community to ensure the data collected was accessible to the co-researchers.

6.3.3 Helping others to engage

In this sub-theme I will highlight how the co-researchers took on the role of "advisor" (Frankena et al., 2018: p.723), supporting their co-researchers in their engagement and providing advice where necessary. A way in which the co-researchers were uniquely positioned to support one another was their knowledge of the other group members interests:

'JC – What sort of things do we want to do? Do we want to be asking people questions?

P4 – We could look on the internet

JC – What are we looking on the internet for?

P4 – How we look after cats

P7 – You mean like uhh what sorts of food for their age and breed and what they're not allowed

P4 – Yeah

P7 – That kind of thing you mean

P4 – Yeah

P7 – I think I've actually got a book at home that says the sorts of things that cats can eat and sometimes what they can't.'

(Transcription_Session_5)

In the quote above, P7 is enabling P4 to engage in the conversations being had and helping them to develop their ideas. By having a prior relationship with P4, P7 was able to interpret what P4 was trying to say. Strnadova et al. (2014) highlight how in their study, the co-researchers identified the importance of “learning and making friends” for team building (p.21). The project discussed in this thesis, highlights how when the process of ‘making friends’ has already occurred, the level of support required from a non-disabled researcher is lessened. The pre-established group meant that trust was already built up (Strnadova et al., 2014: p.20) enabling a supportive group dynamic for every member, with or without a learning disability. This conveys the importance of a group dynamic for these co-researchers. By being able to rely on one another for support to help them engage in the project the co-researchers were more capable in articulating their thoughts and ideas. Furthermore, it created a friendly supportive environment where people weren't judged for what they said.

6.3.4 Leading decision making

The co-researchers in this project, showed clear capacity to lead the decision making, in particular focusing on what they believed they required to further the project fulfilling the roles of “expert-by-experience” and “co-researcher” (Frankena et al. 2018: p.723). The co-researchers in this project showed a clear capacity to make their own decisions regarding the project from the first phase (Chapter 4):

'At the end of this session I felt incredibly flustered. I felt as if I hadn't succeeded in doing what I wanted to achieve, but on reflection, this was because the co-researchers took control and did what they wanted to do.'

In my observations of Session 2 I identified how the co-researchers had begun to take control of the project and required very little support apart from with technical aspects of the project.

From the second phase of the project, the group began to show clear leaders who took on the decision-making roles:

‘During the research plan section, I felt that P4 and P7 took charge of the discussion leading others into ideas and addressing them in their own way. This was the first time I became a co-researcher’

(Observation_Session_5)

In Session 5 P11 was not in attendance, meaning the MLMC staff member was not as aware of the co-researchers and the levels of support they required. As co-facilitator within the group, P7 took charge and would offer support to other co-researchers and speak up on their behalf (as evidenced in the quote in Section 6.2.3).

Furthermore, P7 and P4 often made the decisions in the group and would reflect on other opinions and experiences to make these decisions.

The inclusive research approach applied to this project allowed the co-researchers to take control and explore their ability to support each other rather than rely on non-disabled co-researchers.

Leading the decision making within a project conveys the lack of need for a ‘leader’ role, and how the co-researchers could support one another without external support.

6.3.5 Technical aspects of the task

The technical aspects of this project required the largest amount of support and highlighted an important question as to how scientific research is done and whether it is accessible. In this thesis I define these technical aspects as practical skills required to engage in the task. These may be reading, writing, drawing, or cutting. These creative methods are not typically found within the online citizen science literature, where more traditional methods are employed to allow for the greater physical distance between participants. However, whilst there was some support required, they were a positive and successful tool for engagement “resist[ing] binary or categorical thinking” (Kara, 2015: p.14) and therefore being a more reflexive approach to engage those who may not think in a binary way.

As creative methods were a large part of this project, in particular the first phase, the co-researchers often required support with the technical aspects:

'P4 - you said you want things about hospital

P1 - yeah

P4 - there's this one kidney disease patient charged £400 for hospital parking

P1 - How big are you talking of, how big's the doo dah? I've only got certain space

P4 - you can do it on the back

P1 - Oh yeah I'll do it on the back cut it out.'

(Transcription_Session_1)

The quote above happened whilst the co-researchers were engaging in the 'Collage Yourself' (Figure 6) activity (Chapter 4.2.2).

Figure 16 – Collage example (P2)



During Session 1, although the co-researchers were working on their own collages, P1 and P4 were very vocal about their topics and would often ask others to keep an eye out for anything of interest to their subject topic. These could often be supported by other co-researchers and only required the non-disabled researchers to ensure each co-researcher had the opportunity to engage in the task rather than just support others.

Whilst this did hinder the co-researcher's ability to engage without any support, by providing these types of support I was able to engage in one-to-one discussions with the co-researchers. Furthermore, the co-researchers were then able to engage without facing barriers that could be difficult to overcome in such a short space of time.

It is important that future citizen science researchers identify these barriers with these participants and provide the support required to enable their engagement.

6.3.6 Summary

In this project the co-researchers displayed their capacity to support one another and the importance of "teamwork and collegiality" to have a successful research group (Strnadova et al., 2014: p.21). I argue that the group dynamic played a large part in this, with every member of the group having an equitable role within the decision making and engagement. The inclusive approach applied to this project enabled us to foster an environment where everyone was able to learn from one another.

The sub-theme of co-researcher was used to explore the different ways in which the co-researchers in this project displayed how they gave support and how they required support. In this project, the confidence of the co-researchers played a large part in their ability to engage without support. Kellett (2010) identifies how confidence, self-respect and self-esteem are increased when communities participate in research. This is reflected within this study as the co-researcher's level of confidence increases when they have an interest or experience with the task at hand.

In Section 6.3 I also discussed the different barriers that the co-researchers faced which forced them to seek out support. Kiernan (1999) identifies how research "relies heavily on intellectual skills" (p.46) and therefore the role of the non-disabled researcher is key for developing and supporting these skills. The language used in the survey data made it hard for the co-researchers to interpret and analyse it. The technical aspects of the tasks often made the co-researchers ask for help. It is important to note, however, that not every member of the group faced the same barriers. A key role for the facilitator is identifying individual need and supporting capacity building on both an individual and collective level.

Whilst some struggled to read, others could read alongside them. Some members of the group could not use scissors, whereas others could cut things out for them. The survey data was worked through in a group and in a structured manner. By following a set process and allowing time for these barriers, the co-researchers were able to find a way to interpret previously inaccessible data.

6.4 Environment

I define the environment as the external factors that affected the co-researcher's ability to engage in the project. These were often things that we could not control yet had an impact on the levels of support required for the co-researcher's engagement.

The environment in this project included a group who, other than the introduction of me as the facilitator, already knew each other. The co-researchers already met in the same location, with often the same group members on a monthly basis. There were routines and rules followed by the group that were affected at times by the introduction of this project (Section 5.2.2). It is key to understanding the importance of the environment on this group to learn how to better engage them in future citizen science projects.

6.4.1 Location

The location of this project was a meeting room which had been used by the group for many years prior to this project. However, over the course of the twelve sessions we worked together changes in the location had an impact on the co-researcher's engagement:

'Since we had been disturbed by another group using the community centre before, we decided to close a shutter, however, they still managed to distract the members.'

(JC_Observation_Session_10)

The introduction of a different group meeting next door often caused friction within the group as the new group would invade the kitchen space behind the room we were using. This meant that concentration was broken and that the space was no longer confidential as strangers entered it. Furthermore, because of the presence of this other group the manager of the room often kept cupboards locked. This meant that the group's tea and coffee was locked away in one of the sessions:

'A big distraction was that the MLMC cupboard was locked which held tea, coffee, biscuits, etc. This meant that some of the members had to leave to go to the shop during the break – this took time out of the session.'

(JC_Observation_Session_11)

Whilst these were out of my control, the impact these changes had on the co-researcher's engagement and need for support was large. These distractions often created a need for someone to take control and bring the group back to the task at hand. It also meant that occasionally the co-researchers required more emotional support as these impacted on how they felt in the space.

Another impact on the co-researcher's engagement was the weather. During the twelve weeks of the project, we experienced some severe weather conditions. Occasionally, this impacted on the co-researcher's ability to attend the sessions, and if they did, it affected their mood and ability to engage:

'Another issue within the group was the change in weather. One of the co-researchers had been heavily rained on and this affected their mood in the session.'

(JC_Observation_Session_2)

Again, this was something out of my control, yet the impact of it required more time and space to explore the different emotions which these changes in environment impacted on. By using a reflexive approach and allowing the co-researchers to take charge of the sessions, we were able to create an environment for them to explore these emotions without feeling guilty for not engaging in the task. This was a key type of support which ensured the engagement of the co-researchers.

This study was conducted with a group of people who were already known to one another, and based in a location which the group were already comfortable in. Yet, it is my belief that with appropriate community building similar results could be gained with people who do not know one another in previously unknown locations.

The idea of a "principled space" has been discussed within reference to online learning (Ahmet, nd.). In a 'principled space', teachers, or in a case such as the one discussed in this thesis co-researcher as facilitators, create and follow a set list of principles to create environments which are inclusive in nature (BARC workshop, n.d.). If similar principles are set by citizen science organisers when engaging currently underrepresented communities, they can overcome issues created by a lack of community.

6.4.2 Number and nature of facilitators

During these sessions I was accompanied by another non-disabled co-researcher, P11. They were a staff member with My Life My Choice, who was the facilitator of the session prior to my engagement with the group. This was incredibly helpful when it came to supporting the co-researchers with technical aspects of the task, and for allowing me to collect my data:

'P11 was incredibly supportive again giving me the opportunity to go around and speak to each of the co-researchers.'

(JC_Observation_Session_2)

Yet, whilst having P11 in the sessions was helpful it did cause disruption if they weren't in attendance and instead were replaced by another member of the My Life My Choice staff:

'The main distraction for this day was that the leader of the group (P11) was not attending and had sent another employee for MLMC in her place. This person was unprepared for the session, often leaving the leading and guiding of the session to me (a job which P11 usually does to allow me to work in collaboration with the group instead of leading them).'

(JC_Observation_Session_3)

The difference between these two sessions clearly identifies the importance of having a research team who are consistent. By introducing facilitators who were unknown to the group and who had their own agendas, the co-researchers would need more support.

6.4.3 Routines

As this group had been working together for a long time, they had set routines which they would follow each time they met. Figure 16 is an example agenda from the group. Each meeting would involve an icebreaker activity planned and run by the MLMC support worker, reading out our group agreements and a break to share news. If there was a change in the routine of the group, this would impact on the co-researcher's ability to engage in the activity.

One time this was particularly prevalent was when P11 had forgotten to bring in the traffic lights they used to ensure nobody in the group spoke over one another. Without these, there was a large amount of friction within the group which required more interaction from myself and P11 to keep the environment friendly.

Figure 17 - My Life My Choice Agenda

my life my choice

Banbury Group February 2020

Our Goals for today

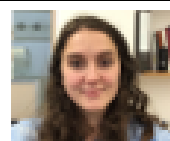
Getting to know each other better ...
Welcoming anyone new to the Group



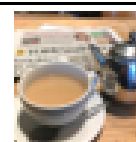
To look at why we are here today and to
look at our Group Agreements ... Trying
New Things



Citizen Science Project with Jess – pick a
leaflet design and some group Work



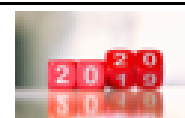
News and a cuppa – what have you been
doing since we last met?



Citizen Science Project with Jess ... more
group work



Banbury Group 2020 ... business



Date for next meeting: Thursday the **26th March 2020**

6.4.4 Summary

In this project, the environment in which the research took place had a large impact on the level of support required by the co-researchers to engage. By using a mixture of known and understood routines with a number of new ways of working, the co-researchers were able to engage in a largely familiar way. Furthermore, by gradually introducing new routines to the group, the project became a part of the routine itself.

The location in which the project took place also played a large part in the co-researcher's engagement. In this project, it was fortunate that we were able to use a location known to the co-researchers. Through the changes that happened to the location during the project we can identify the importance of having somewhere familiar for the co-researchers. The familiarity removes further distractions and allows the co-researchers to feel comfortable within the space. However, this does not mean that an unfamiliar location could not be used for studies of this nature. When planning a project, citizen science organisers must aim to create a safe or "principled space" (Ahmet, n.d) in which the co-researchers can feel comfortable when learning.

Lastly Section 6.4, I identified how the number and nature of the facilitators involved impacts on engagement. When removing a regular member of the group and replacing them with someone unknown, trust, rapport and confidence must be rebuilt, and distractions can occur. I argue that the importance of this to this project lies in the regularity of a group, the significance of key group members i.e. P11, as a facilitator of the group.

6.5 Discussion of Support

The theme of support has focused on the discussion of three sub-themes. Firstly, I discussed the role of the co-researcher within this study. The data showed how the co-researchers supported one another to develop and learn research skills. Within the group, each co-researcher played a different role and were able to support one another with different aspects of the tasks. Next, I discussed the importance of a stable and safe environment in which the co-researchers could explore citizen science. Finally, I discussed the role of facilitator and how within this study, it was mainly focus based support required from the non-disabled researchers to enable the group to stick to time frames.

Through understanding the different support requirements when engaging people with learning disabilities in citizen science, we can better design these activities to be more inclusive and ensure we

aren't excluding this community and their valued voices within this discourse. Furthermore, it was key within this project that the support given valued the skills and provided opportunities for ownership by acknowledging that everyone is "different but equal" (Bigby et al., 2014: p.61).

The main objective of this research study was to understand what support people with learning disabilities require in regard to their capacity to engage with citizen science. In this chapter I have outlined the importance of a group dynamic to supporting people with learning disabilities. By adopting an inclusive approach and following Walmsley & Johnson's (2003: found in Section 2.4.1) principles and transferring "control over the process and outcomes" (p.64) to the co-researchers, they were able to build their own confidence and learn new skills in a supportive environment.

During the analysis of the data I identified how within the group dynamic a hierarchy developed. The co-researchers with more skills and experience took over the discussions and often took on the responsibility of supporting those with fewer skills. This highlights a key question in inclusive research, can research ever be truly equal or will a hierarchy always naturally occur. I argue that in this particular study the co-researcher's level of power in the group depended upon their confidence with certain research skills. Furthermore, the inclusivity of this study stemmed from the co-researcher's ability to change the hierarchy and advocate for themselves instead of non-disabled researchers doing this for them. I refer to Nind's (2008) question as to whether research is with, for or on. By understanding the co-researchers support needs and allowing other co-researchers to provide the help the hierarchical nature of the research adapted to allow for each member of the group to convey and develop their skill set. This ensures that the research is collaborative and conducted "with" the co-researchers.

A barrier within this research was the impact of technology. I identify within the discussion above how many of the co-researchers were not comfortable with or had not ever used technology before. As Holliman and Curtis identified in 2015, citizen science has moved towards using the "digital landscape" to reach possible participants. Yet, this study has identified that without the appropriate support and training a technology-based approach to citizen science could exclude communities without access or knowledge to the appropriate technologies.

Above I have highlighted two of the key findings of the support theme within this research. In the next chapter, I will explore these alongside the findings from Chapter 5 in more detail and look at what citizen science can do to be more inclusive of the learning-disabled community.

Chapter 7 – Discussion and Conclusions

7.1 Introduction

Can an inclusive approach meaningfully engage people with learning disabilities? At the beginning of this thesis I highlighted how UKRI (2019) outlined four aims in their *2019 Delivery Plan* for public engagement with research. The first of these aims was that “everyone in the UK has the opportunity to participate in research and innovation” (p.33). This thesis has explored whether citizen science was fulfilling this aim, and what more it could be doing. In this final discussion chapter, I will answer the overarching question of whether an inclusive approach can meaningfully engage people with learning disabilities. Further, I will offer some theoretical and practical suggestions to inform the practices of those organising future citizen science activities.

This thesis is grounded in the theories of inclusive research, citizen science, public engagement, and capacity building (Chapter 2). Drawing on these four approaches to research, this study aimed to engage adults with learning disabilities in a form of participatory scientific inquiry. In combining these four approaches, this study has explored whether, by creating a space to both learn and practice new skills, the learning-disabled community could be supported in meaningfully engaging with citizen science.

Through careful upstream planning, allied with a reflexive approach, the study built capacity in citizen science, catering to the needs of the core needs of the group and their individual requirements for engagement. In addition, a reflexive approach allowed the co-researchers to gradually take greater charge of their learning and lead the study in the direction they wanted it to go, whilst the facilitator continually re-assessed need, adding and removing support at a collective and individual level as required.

Irwin and Wynne (1996) suggest that “lay-people” have the ability to be reflexive and “develop their own social position” in response to scientific expertise (p.43). This project has shown that a facilitator of citizen science research is pivotal; they also need to build their capacity to be reflexive, to genuinely enable different communities to engage in scientific inquiry. Citizen science organisers need to move from an expectation of reflexivity from the participants, to be more reflexive in their own practice if they are to engage currently under-represented communities. Wehmeyer (2014) suggests that researchers need to approach engaging the learning-disabled community with training in mind. Through training and support people with learning disabilities can make meaningful contributions.

This again highlights the significant role of the citizen science organisers in embracing inclusivity. To do this, they need to adapt, be exposed, and build their capacity. The key issue for citizen science organisers is to create detailed plans in advance for different scenarios. Furthermore, throughout the process the facilitators need to be willing to adapt, to make judgements about how much support is required collectively and individually in practice.

Using the principles of critical research (Section 3.2), this thesis challenged the power distribution within research. Firstly, this thesis identified how the learning-disabled community had been overlooked in the citizen science literature (Section 2.2). Engaging the learning-disabled community as ‘co-researchers’ as opposed to passive participants requires a change in language and practices; the inclusive research methods created a space for equitable opportunities within this research. This reflects the principles of inclusive research set out by Walmsley & Johnson (2003) in which they state, “that people with learning disabilities need to be treated with respect by the research community” (p.16). The thesis highlights how, by taking time to develop shared respect between researcher and co-researcher and an understanding that everyone’s support requirements matter, engagement of currently ignored communities is possible.

Overall, this thesis has shown that the merging of different approaches to of the co-production of knowledge can engage the learning-disabled community.

7.2 Addressing the Research Questions

In Chapter 1 I outlined the research questions. In this Section, I will discuss each question independently, highlighting key findings.

7.2.1 Research Question (a). How do people with learning disabilities understand research as a process that underpins citizen science?

To discuss this research question, I will break it down into three parts to understand the co-researcher’s interpretation of research as a process that underpins citizen science.

7.2.1i How do people with learning disabilities understand research?

The co-researchers of this project began their exploration of citizen science by first engaging in a collaging activity in which they defined what research meant to them. Through this activity, they developed a shared understanding of research, whilst also exploring the general purpose of research

(Section 4.1). This initial activity and the resulting artefacts (e.g. collages, identity boxes – refer to Figures 10 & 11) created the foundations of the capacity building programme, as well as building rapport between the facilitator and co-researchers (Chapter 4). Their understanding of research was highlighted through topics which had a personal relevance to them.

When discussing citizen science, Irwin (1995) identified how there is a “perceived *need for* and *relevance* of science and technology within everyday life” (p.34). This, he argued, is what can bring science closer to citizens, and citizens closer to scientists. The co-researchers of this project “perceived [a] need for” research in general to relate to their personal interests and issues relevant to their community. The co-researchers of this project chose to focus on four topics with personal relevance (Section 5.8). Each of these focuses on helping a certain community using research and have a link to impact and change within larger issues.

The implications of how people with learning disabilities understand research for citizen science are that this community should have a role upstream in selecting topics for research. This community can identify issues with wide-ranging impact and relevance to them. The learning-disabled community can offer a different view on issues of relevance to them because of their individual and shared lived experiences. By understanding and highlighting these, citizen science can engage this currently under-represented community in scientific inquiry and utilise the expertise and experience of this group.

7.2.1ii How do people with learning disabilities understand research as a process?

When doing their collages, the co-researchers identified three different aims of research: Improve, Stop, and Help (Chapter 4.2.3). Holliman (2017) discusses the need to actively explore motivations to engage, such as these identified by the co-researchers of this study, to create a shared purpose for research. The framework of Improve, Stop and Help is suggested here as a useful way of exploring how others might frame their understanding of research as a process. It can be employed to explore how other underrepresented communities frame their motivations for engaging with citizen science projects. The framework is suggested here as an initial starting point, from which researchers can adapt to suit their research and the community’s needs. I will discuss this framework below in relation to the co-researchers identified aims of research.

Improve

The aim of ‘improve’ focuses on how research can be used to have an impact, and ‘improve’ something that may not be adequate. Through a lens of improvement co-researchers can explore how

research can have an impact on certain communities, e.g. those living with learning disabilities. This links to Holliman's (2017) "substantive" rationale for research in which the researchers' question "what types of expertise and/or experience are likely to improve the research and/or the social and/or economic impacts derived from it" (p.5).

Stop

Similar to the previous aim, 'stop' allows researchers to explore whether research can have a positive impact on a negative issue. In effect, how can an evidence-based approach reduce negative impacts. In this case, this impact also affected a certain community (learning disabled).

Help

The aim of 'helping' refers to using research to 'help' a different community. Again, like the previous two aims, 'help' denotes a certain level of impact on a specific community. As such, each of these lenses offers a view of research to effect change, effect or benefit.

Each of these aims refers to a certain level of impact, whether this be at a community level (i.e. us) or a national level (i.e. hospitals). Each of the topics suggested within these aims was related to the co-researcher's lived experiences, displaying a wish to have a voice within research instead of having others doing it on their behalf (Chapter 5.10).

This aim, I argue, links to Holliman's (2017) normative rationale for research, both in terms of a moral imperative to improve lives, but also in relation to "who should have a voice in research?" (p.5). In this project, and with this research aim, the co-researchers are conveying that they want to have a voice in research, and particularly in topics that have relevance to them and to which they can bring direct experience and expertise. But it doesn't stop there. The co-researchers also believe that their voices can 'help' other communities. From this, I argue that the co-researchers not only convey a focus on impact, but in fact focus this impact on communities, including those separate to their own.

These three aims all link to 'altruism' and its "ultimate goal of increasing the welfare of another" (Batson & Shaw, 1991: p.119). This motivation to do research links to the discussions of motivations to do citizen science (Chapter 2.2.3). Altruism is described by Jones et al. (2018) in relation to citizen science as a "desire of citizen scientists [to] contribute to scientists and science without compensation or significant benefits to themselves" (p.289). This links to the co-researchers aims, as they perceive research to be about 'stopping', 'helping' and 'improving' both their own communities and others.

This makes clear their motivation for doing research, linking to their topic choices with personal relevance. Whilst the topics have a personal connection, they also have a larger impact on both their communities and others.

By suggesting that research can either ‘improve, stop or help’ their community, the co-researchers demonstrate an understanding of ‘self-advocacy’. My Life My Choice define ‘self-advocacy’ on their website as “people with learning disabilities being in control of their own lives...speaking up about what they want and being listened to. It means being able to choose things for themselves” (My Life My Choice, n.d). This definition conveys how self-advocacy is about an understanding of issues facing the learning-disabled community and speaking up about these issues. The co-researchers in this project show an understanding of the issues and showed this through their collages. As this project was conducted with a ‘self-advocacy’ charity, it’s important to note that this capacity may need to be built with other groups. The first phase of the project described in this thesis was aimed at providing groundwork and would be an ideal place for future researchers to build the self-advocacy capacity.

This returns to the ideals set out within inclusive research that research should be done with people with learning disabilities as co-researchers (Walmsley & Johnson, 2003). It also refers to the ideas of self-advocacy, that members of a community *should* have a voice in informing change through evidence-based approaches (Holliman, 2017, my emphasis).

This poses an interesting question, as to who should have a voice in research, and how are they supported in making meaningful contributions (Holliman, 2017)? It is a question seen across the literature regarding citizen science, inclusive research and many other research approaches. The co-researchers in this project have identified that they believe they deserve a voice in research. However, they also identified that other people have voices in research. What then, has been learnt through this research that could inform a research project across communities? For example, if the learning-disabled community choose to do a citizen science project into hate crime, should this involve just the learning-disabled community or work across different communities who are impacted by hate crime e.g. minority groups and police officers? This brings into question the notion of representation in research, and how publics are created and represented. Mahony (2015) discusses how, in public engagement, researchers should consider how publics are represented, whether they are segmented or self-selecting and how they are targeted (p.6). These questions are key for citizen science organisers who may wish to engage more than one community in research projects. By understanding the representation of publics within research, facilitators can adapt their practice to suit the community’s

needs. Who has a voice in research, and how they are supported to engage, should be considered together (Holliman, 2017). I will discuss this in more detail in Section 7.6.

Figure 14 in Chapter 5.8 highlights how the co-researchers of this study identify the different levels of research as ‘personal, community and national’. Furthermore, these levels link a group understanding of the larger research process. Often, an idea is formed at a personal level perhaps linking to a personal experience. This is then opened to focus on a community, using this community as the co-researchers. Lastly, the impact from the research has the potential to be national when it engages policy makers.

Within citizen science, projects span many different levels. These span from beginning a project on a platform like nQuire where the topic has a direct interest to you (<http://www.nquire-it.org/#/project/3801089>) to national campaigns such as GalaxyZoo. This applies to research, which the co-researchers of this project identified. My Life My Choice, the charity of which the co-researchers of this project are members, conducts campaigns across all of these different levels. This is how the co-researchers have direct knowledge and experience of these different levels of research.

The co-researchers’ understanding of research, through its different aims and levels, links to motivations found within the citizen science literature. In Chapter 2.2.1 I briefly discussed Batson et al.’s (2002) motivations for engagement: egoism; altruism; collectivism; and principlism.

I argue that the co-researchers’ understanding of research as a process reflects each of these motivations. The first part of the definition, topics, reflects the motivation of egoism. To the co-researchers, research connects with individuals more directly when there is a focus on a topic of personal relevance to them. The next part of the definition aims, reflects altruism, collectivism and principlism. The co-researchers discuss how research can be used to help, stop or improve issues not only relating to their own communities’ welfare but to others as well. This displays how motivation is key in engaging people in scientific inquiry, but it’s crucial for researchers to understand how motivation can come in many different forms. Furthermore, these three aims convey a clear moral motivation where research should be used to impact positively instead of for personal gain. Thirdly, the different levels of research reflect the different levels of welfare discussed in Batson et al.’s (2002) motivations. Whilst the co-researchers reflected that research could have a personal impact, it can also be used to help a community and to impact on national policy.

Finally, I argue the theme of self-advocacy reflects all the above motivations. The co-researchers recognise the need to have a voice, but also identified that their voice can be used to support many

other communities. This not only displays an awareness of the importance of others welfare, but also an understanding of the morals surrounding research about using your voice and experience to have positive impacts on communities either excluded or not previously heard. This conveys how research with people with learning disabilities does not only have to focus on their lived experiences. Their knowledge and interests span far wider than this. This is key for both citizen science organisers and inclusive researchers, as they can begin to look at engaging this currently under-represented community in research with wider interests. It is not a lack of knowledge or personal experience that excludes the learning-disabled community from citizen science, but rather the lack of capacity building and the approach taken by organisers to engagement.

7.2.Iiii How do people with learning disabilities understand research as a process that underpins citizen science?

To address the full question above, I first want to highlight how the co-researchers understood citizen science and our shared understanding of the term. Again, this was broken down into activities within sessions during the first phase of the project, first looking at the term citizen and then defining a citizen scientist. These activities also helped to build rapport between the facilitator and co-researchers and introduce new ways of working to pre-existing routines within the group.

In the third session of this project, I encouraged the co-researchers to think about and discuss how they might define a citizen (Chapter 4.2.3). Section 2.3.1 highlighted the importance of labelling as a concept, and how labels can be detrimental to a citizen's engagement. There is still a trend in the citizen science (and some of the public engagement) literature to refer to 'the public' as "a homogenous mass" (Irwin & Wynne, 1996: p.9). The co-researchers shared understanding of a citizen, whilst generalised, identified that citizens could be many things. Their identification that they were indeed citizens with agency, was key to creating a sense of belonging for the co-researchers with the citizen science community. By avoiding shorthand and potentially negative labels, and instead focusing on positive traits and diversity, the co-researchers were able to project themselves into the role of 'citizen scientist' and remove typical barriers they might face to belonging (Strnadova et al., 2018).

In Chapter 4.2.3 I outlined the group's definition of a scientist, followed by their description of a citizen scientist.

These exercises were conducted at the beginning of the study and allowed the group to create a shared understanding of what they believed a scientist to be. Furthermore, it created a space in which to discuss and unpick any negative connotations about science that the co-researchers may have gained from both personal experience and the wider society. My Masters study (Carr, 2018) identified how by being engaged in positive scientific experiences, the participants were able to view themselves as scientists and move past these negative connotations. Therefore, by creating a shared understanding of research and those who conduct it, we were able to build both the co-researcher's confidence in doing research and understand their capacity needs. This was key foundational work within this project, as it allowed the co-researchers to begin to picture themselves as researchers and through the groups shared understanding, we were able to progress through our research and build our capacities as researchers. As discussed in Chapter 2.3, the learning-disabled community have experienced prejudice and exclusion within many parts of their lives. The first phase of this study created an opportunity to introduce measures to both counter the exclusionary practices and build confidence.

7.2.1iv Addressing the 'big picture' question

Sections 7.1 and 7.2 have addressed the 'big picture' question: 'How do people with learning disabilities understand research as a process that underpins citizen science'. First, I discussed how the co-researchers of this project understood research as a process. The data from the physical project identified how the co-researchers understood research through its different aims and levels. The key factor of both was the impact it could have on not only the learning-disabled community, but also wider communities affected by similar issues.

I next discussed the co-researchers' understanding of citizen science. The co-researchers were able to identify and define both the terms of 'citizen' and 'scientist' and identify themselves as citizen scientists. This is key to a sense of 'belonging' within citizen science and highlights the importance of removing negative labels and instead focusing on ensuring the people engaging with citizen science "feel 'at home' within [the] community" (Strnadova et al., 2018: p.1098).

When introducing the project to the group they had no prior knowledge of citizen science but did understand self-advocacy and its links to research. Hence, through extended engagement with the co-researchers I was able to identify a relevant area of experience through which to build capacity. This highlights how within this project, the co-researchers understood research as a process, but not necessarily how it is related to citizen science. Section 2.6 questioned the assumption that when

capacity building that people have “at least a fundamental grounding in research skills” (Nind, 2016: p.543).

This project has highlighted that whilst the co-researchers of this study understood the process, they did not possess “a fundamental grounding” of the research skills required for citizen science. This thesis has shown how this “fundamental grounding” can be taught through a scaffolded approach allied with sophisticated facilitation. Therefore, it is important for citizen science organisers to move away from this assumption and instead focus on research training to build the “capacity of researcher” (Strnadova et al., 2014: p.20) to engage the learning-disabled community.

7.2.2 – Research Question (b) Does a structured approach to capacity building support people with learning disabilities in their engagement with the research process?

The second research question focused largely on the inquiry process, and whether applying a structured approach to capacity building would increase the engagement of the learning-disabled community. The data from the project highlighted how important flexibility was for enhancing the engagement of the co-researchers. The first phase of the project was developed around the concept of building confidence and self-efficacy in the co-researchers and developing rapport between us as a group. By allowing the co-researchers to guide aspects of the agenda and adapt sessions where they felt necessary, the co-researchers were then able to engage in ways that suited them. This meant that between sessions, plans had to be reviewed and revised to reflect what the co-researchers wanted from them. This highlights a practical requirement of time between sessions for this to be completed and identifies the importance of the non-disabled researcher’s role for enabling “participation in research” (Walmsley, 2004: p.66). This approach created a potentially problematic methodological issue where I could not be certain where, or how, the project would finish. This could create issues when gaining funding for this form of research as the remit for funding would need to be broader and allow more flexibility for planning.

Another key finding from the data was how the co-researchers displayed different literacies, enabling them to engage up to a point in the inquiry-based tasks. However, the research training offered within the project furthered this literacy and created a structured environment for the co-researchers to explore their own capacities and identify where they might struggle to engage. The time in between sessions (1 month) created a challenge however, as the co-researchers would frequently forget terminology. This was overcome through the production of materials with the terms including definitions understood by the co-researchers each session (Appendix F).

The support required in this project was largely based around structuring, however, this was often separate from the citizen science and inquiry process. The structuring needed to further the co-researcher's engagement was highlighted in the 'prompting to focus' sub-theme (Chapter 6.4.4). The data under this category showed how the co-researchers could perform the tasks yet often needed reminding to stay on task.

To discuss this question in more detail, I will return to the findings of Chapter 6 and explore the different support required by the co-researchers. Furthermore, I will highlight how these forms of support enabled the co-researchers to engage in the research process.

7.2.2i Role of the non-disabled researcher and the capacity building programme

As highlighted in Chapter 6.4, the role of the non-disabled researcher (and support worker from MLMC) was to plan, react and adapt to the co-researchers' needs and wants for the project to ensure there was every opportunity to engage. Within this group, the non-disabled researcher's role was to provide task-based support. In the context of this project, this involved bringing focus back to the task and supporting co-researchers with physical or communicative challenges they may have faced during their engagement. Through the employment of a reflexive approach, this role became less and less integral to the group's overall progress as the group began to take ownership of the project. However, it was still required for discrete tasks, and to support individuals. The reflexive approach to researching in this project, enabled the non-disabled researcher to consider their practice within the sessions and adapt it for the next meeting.

The capacity building programme within this project was structured to provide a timeline in which the co-researchers could learn a new research skill, then put it into practice. The first phase of the programme (Chapter 4.2) was largely creative and focused on engaging the co-researchers with the idea of research and encouraging them to think about their role within the research community. Through the creative tasks the co-researchers began discussions about research topics which influenced the planning process for the citizen science project. The creative tasks used within the first phase were selected to encourage "motivation, innovation and problem solving" (Reilly, 2017: p.26). The data from the study suggests that the creative tasks had the highest levels of engagement, due to the co-researcher's enjoyment of the tasks. This identifies how, when working with the learning-disabled community, researchers and science communicators need to adapt their approach to create more engagement opportunities who may not engage with more traditional methods.

The second phase of the project (Chapter 4.3) was initially planned to offer one training session for a research skill (i.e. data collection or analysis), followed by one or two sessions for employing the skill. However, certain aspects of the project took more time than had originally been anticipated where other aspects took less time. The planning and analysis stages of the project took three to four sessions to complete whereas the data collection took only one session as the co-researchers chose to use a survey. Reflecting upon this issue, it identifies the importance of flexible scheduling to a programme such as the one created for this project. By employing a structured programme of research training, over a course of eight sessions, the co-researchers were given the opportunity to engage in research in their own time and in a supportive environment.

The first two phases of this study stuck broadly to the original aims; it was the detail of the sessions that was adapted. The third phase was forced to change due to the Covid-19 pandemic, and the social distancing measures put in place. Reflecting on this, the main challenge for citizen science organisers would be the flexibility of funding requirements. As many funders request detailed plans and aims for studies, and these need to be consistent throughout a study, funders would need to become more flexible to allow for adaptations to be made.

In this project, the role of the capacity building programme was to offer a structure to research skills training. The result, a successful citizen science project, provides evidence that the structure was successful. However, there were obvious challenges, which I will reflect on in Section 7.6.

7.2.2ii Role of the co-researcher

Chapter 6.2 of this thesis focused on the role of the co-researcher, and the vital support they provided to encourage the groups engagement.

The key points that were highlighted in the discussion of the data showed how the co-researchers were able to identify their own skills and had confidence in using them (Chapter 6.2.1). Furthermore, they were confident in supporting others within the group and helping them to develop these skills. An example of this was P4, who had technological literacy. They used this to support other members of the group, such as P8, who had never used technology in this context before. The inclusive and adaptive nature of this project enabled the co-researchers to take control in situations such as this and removed certain aspects of the non-disabled researchers' role.

7.2.2iii Addressing the research question

Section 7.2.2 has addressed the question: ‘Does a structured approach to capacity building support people with learning disabilities in their engagement with the research process?’ I framed the discussion of the answer through the different roles within the group. Firstly, I discussed the role of the non-disabled researcher. The data from the physical project identified how throughout the process the co-researchers required some form of support from the non-disabled researcher, reflecting Walmsley’s (2004) suggestion that the non-disabled researcher’s role is vital for this form of research. A key part of this role was largely to encourage the co-researchers to stay on task. Furthermore, support was often needed with physical or communicative parts of a task e.g. cutting things out or reading text. This identifies how the non-disabled researcher was a key member of the group, yet the data did not show whether the group could engage in the project without them. This would require further research.

The group dynamic provided a form of structure to encourage engagement within the research process. This was evident through the co-researcher’s roles within the project. They provided support to other members of the group by identifying and being confident in their individual skills. This, I argue, highlights a key part of the capacity building structure within this project, group work. Strnadova et al. (2014) similarly identified the importance of a group environment, and how the co-researchers in their study discussed how “learning and making friends” (p.21) was key to creating a supportive and successful team. By engaging the co-researchers in group work alongside lone work, they were able to support one another with their engagement in the research process. Over time, this allowed them to have ownership over what they were creating and remove certain aspects of support such as leadership from the non-disabled researcher.

The result of this project is not only this thesis, but a leaflet created by the research group. This leaflet provides the evidence to identify how this community of adults with learning disabilities were not only able to engage with the research process but have a successful outcome (Appendix A). The capacity building programme provided the co-researchers with the structure and opportunities to learn new skills which they then put into practice.

7.2.3 – Research Question (c) Do methods derived from inclusive research support engagement for people with learning disabilities with citizen science?

In Chapter 2.4 I discussed inclusive research and the influence it had on this project. I highlighted key principles found within the literature that would guide the approach used and the methods employed.

Creative research methods were used in the first phase of this project (Chapter 3.3.1 and Chapter 4.2) to encourage an inclusive atmosphere where the co-researchers could engage with topics relating the project in ways that suited them. In Section 7.2.3, I will discuss how the qualitative methods used within this project supported engagement for the co-researchers. Next, I will highlight key parts of the data that identify how an inclusive approach enabled the co-researcher's engagement.

7.2.3i Use of qualitative methods

Inclusive research largely relies on qualitative methods to create an inclusive environment (Chapter 3.3). In this project, the methods employed were two-fold. First, I will discuss the methods used to collect data for this project. Second, I will discuss the capacity building programme and how the methods used here supported engagement for the co-researchers.

The qualitative methods employed were a mix of creative and traditional (Chapter 3.3). Both forms of research methods were grounded in an inclusive approach. In the context of this project this meant removing barriers to engagement, being “collaborative” (Walmsley & Johnson, 2003: p.64) and “empowering” (Woelders et al., 2015: p.528). The creative methods were planned to provide a structured and supportive environment in which the co-researchers could explore potentially difficult topics, such as identity. In the final interviews of the project (Chapter 4.4) the co-researchers highlighted how the creative methods were their favourite part. These methods also had the highest level of engagement from the co-researchers. It was during these creative tasks that I first noted, as planned for, the co-researchers taking control and ownership over the project. These research methods were key to engaging the co-researchers in the project, and by employing them first created an effective way to promote engagement within the group. This can be seen within the inclusive research literature, where creative research methods are employed (Ollerton et al., 2012; Kennedy et al., 2014).

The capacity building programme within the project was designed to create opportunities for inclusivity. As discussed in Section 7.2.2, the programme was designed to build capacity in research skills then provide opportunities for the co-researchers to put them into practice. Whilst it could be argued that the capacity building element of the programme created the need for a ‘facilitator’ role (Chapter 6.4.2), this also gave the co-researchers the skills they needed to complete a research project themselves. Therefore, I argue, that the capacity building programme itself is an inclusive method to research with adults with learning disabilities. Furthermore, it provides the support necessary for the co-researchers to engage as vital parts of a research team within the research process.

7.2.3ii The key benefits of an inclusive approach

During the project, an inclusive approach was used to create a supportive group dynamic and structured approach to achieve a purposeful end. This was highlighted through the co-researcher's capacity to support one another, and equitable ownership of the project (Chapter 6.2.4). The data from the project showed how certain co-researchers began to take on leadership roles, changing the power dynamic. Furthermore, these co-researchers would often be the ones encouraging engagement from others within the group (Chapter 6.2.3). However, the non-disabled researcher was still needed to provide practical support where necessary and encourage the group to focus on the task. This sometimes disrupted the inclusive dynamic, and on reflection reinforced how the power lay with the non-disabled researcher. This issue, however, may not be present when there is less at stake for the non-disabled researcher (i.e. PhD), but this would require further research to confirm.

7.2.3iii Addressing the research question

The inclusive methods within this project created multiple opportunities for the co-researchers to engage with citizen science. The creative tasks created an enjoyable and productive way to encourage the group to work together on difficult topics and begin to discuss the potential for their research. Furthermore, the capacity building programme, which was grounded in inclusive principles (Section 2.4.1), engaged the co-researchers as part of the research community. It provided them with the skills to continue researching outside of this project and advocating for their community. The data from this project highlights how these inclusive methods did engage the co-researchers in citizen science by furthering their skills and confidence in the research process.

Having discussed the research questions on which this thesis is based, I will now move on to discuss the issues raised within the thesis, and how these were addressed within the project.

7.3 The sum of the constituent parts

Part one of this thesis explored the literature around citizen science, learning disabilities, inclusive research and capacity building. By critiquing and discussing the current literature, this thesis found the gap in which it sits and identified the questions it needed to ask.

The discussion of the citizen science literature highlighted how the current literature identifies potential participants as “plural and heterogenous publics” (Dawson, 2018: p.773). This term is helpful; my practical approach demonstrates that when design is carefully thought-through, groups and

communities can work together. Thinking about how to adapt citizen science and build capacity for different ‘publics’ is essential, however, as Dawson (2018) notes the solution is not “as simple as getting more people through the door” (p.784). Instead, it is key to identify relevant publics, and where possible and relevant to certain groups, meet them in their own surroundings.

The discussion of exclusion criteria in the literature, whilst identifying reasons for exclusion, does less to suggest practical solutions to remove these barriers. Some authors go as far as to argue that responsibility to engage and remove these barriers lies with the ‘public’ and their citizenship ‘rights’ and ‘duties’ (Allgaier, 2010). This thesis challenges that idea by arguing that those organising citizen science activities should be more willing to adapt their practices to engage a wider range of communities and to actively explore exclusion. The findings suggest that citizen science organisers need to adapt their ways of engaging communities, using the principles of upstream and downstream engagement (Wilsdon and Willis, 2004) to become more inclusive.

The learning disabilities literature discussed in this thesis focused largely on the ideas of labelling and identity. It highlighted how the current field of thought is that the label of ‘learning disabilities’ has negative connotations and can be a barrier to this community being treated as ‘citizens’ (Morris, 2005). This had strong links to the critique of the equal citizen science literature, and the importance of engaging ‘publics’ in different ways. The citizen science community need to develop ways to identify publics different needs that aren’t focused on negative labels. By not grouping all citizens together and instead understanding and valuing their different skills, citizen science can become a tool for participation “for all” (Silvertown, 2009). The capacity building programme outlined in this thesis highlights how through offering opportunities to share and develop skills within the group of co-researchers, they were able to support one another with little help from the non-disabled researcher as is supported within the capacity building literature (Bigby et al., 2014).

The discussion of the inclusive research literature highlighted how the current and most prominent literature focuses on the process over the outcomes of the research. As a relatively newly field (Walmsley & Johnson, 2003) the inclusive research literature is still developing as more research projects are reported, such as this thesis. This thesis argued that by combining citizen science and inclusive research, we can further both fields and create new inclusive and equitable forms of public engagement. I argue that there is much to be gained from sharing learning between these fields.

The final topic discussed within part one of this thesis was capacity building. The key points raised within this discussion were of the potentially negative aspects of employing a capacity building

programme. The question raised here was whether by facilitating research skills training, are we ignoring the different forms of capacity that the participants already have? This links to the discussion of the citizen science literature, whereby it was highlighted that by grouping all citizens together as one ‘public’ we are ignoring individual needs and skills. I argue that there is so much to be lost if we continue “seeing people as masses” (Williams, 1989: p.11).

This study used what was learnt from the discussions outlined within part one of this thesis to create an inclusive research project (outlined in part two). By combining the issues raised within the literature review this study aimed to be equitable and acknowledge each research member’s skills and provide a supportive environment in which to explore these.

Part two outlined the methodology and methods used within the study (Chapter 3) and provided a detailed description of each session (see Chapter 4). Part 2 explored the creative research methods and how the application of them required reflexivity on the part of the facilitator. The sessions also described the capacity building programme, emphasising the need to be creative and flexible in the earlier sessions (Phase 1). By reflecting on each session and the co-researchers’ needs, the non-disabled researcher was successful building confidence and skills, engaging the co-researchers in conducting their own citizen science project.

Part three documented the findings. Chapter 5 reported the findings relating to the theme of capacity. Here, different barriers to engagement were identified. For example, the distractions of their personal lives were highlighted as a key barrier to the co-researcher’s engagement. However, by allowing more time within the sessions, discussions could be refocused on the research. Furthermore, by allowing these distractions to influence our scientific inquiry we were able to create something which had an impact on many of the co-researchers. This was key to the inclusivity of this research as it created more opportunities for the co-researchers to lead the agenda of the project. Nind (2017) highlights how inclusive research must “represent [people with learning disabilities] lived experience” (p.278). By creating space and time for conversations about their experiences to occur, Chapter 5 shows that this is both possible and necessary.

Another barrier identified was the co-researchers perceived lack of literacies required for engagement. One of these literacies was scientific literacy. Durant (1994) defines scientific literacy in three ways, the latter as “the understanding of how science really works” (p.83). The co-researchers in this study displayed this understanding, whilst also expressing how they thought science and research ‘should’ really work (Section 7.2.1ii). What isn’t discussed as much in the citizen science literature are the

other literacies identified within this project that are needed when citizens engage with science, such as reading and writing, and inquiry (Section 5.7). Using the capacity building programme, barriers to these literacies were identified and overcome. The skills of each co-researcher were able to be highlighted and used as a training tool for others, demonstrating the value of engaging with a pre-existing community.

The data from this study also highlighted how many of the co-researchers were able to reflect on their experiences and knowledge and use these to influence the research. These lived experiences were often different to those of the two non-disabled co-researchers in the study (myself and P11) and highlighted how this community can bring a new world view to citizen science through their unique voice. This reflects the capacity building literature (Section 2.6), which highlights capacity building should encourage the development of capacities whilst not losing “valuable insider” perspectives (Nind et al., 2016: p.550). I argue that this was a key success of this study, shown through the co-researcher’s constant input and influences on all parts of the research project.

The second discussion of findings focused on the theme of support (Chapter 6). This theme was split into three sub-themes: co-researcher, facilitator and environment. The sub-theme of co-researcher highlighted how each member of the group had different skills that they were able to share with the group. These impacted on the research study and often created opportunities for learning and teaching. By highlighting and using each individual’s skills, we were able to avoid “wasting resources teaching” (Bigby et al., 2014: p.62) and instead focus on employing a “collaborative recursive process” (Inglis and Cook, 2011: p.103) which fostered a more collaborative learning environment “learning from and with each other” (Nind and Vinha, 2014 (b): p.103). The role of ‘facilitator’ within this study was discussed through its focus-based support. As Walmsley (2004) identifies, the role of the non-disabled researcher is “vital” to the “participation in research” of the co-researchers (p.66). In this project, the role of the non-disabled researcher was practical, in that it largely concentrated on encouraging the co-researcher’s participation and focus on the project. This was often due to time frames that needed to be adhered to and if timings were to be more flexible, this role could develop further. Finally, the sub-theme of environment highlighted the importance of a stable and safe environment for engagement, in which a community could be built such as a “principled space” (Ahmet, n.d.). By creating and following routines, this group of co-researchers were more comfortable in their engagement, knowing what to expect of each session.

A key barrier to engagement discussed in both the capacity and support themes was the impact of technology. Seale (2007) identified how fewer people with disabilities owned computers than their non-disabled counterparts. This identifies an issue with access to technologies, which is a particular concern with citizen science as the “digital landscape” within this field continues to grow (Holliman and Curtis, 2015). The digital divide within this group highlighted how a lack of training and support with technology-based citizen science could exclude the learning-disabled community (Section 7.4.2).

7.4 Practical suggestions

This thesis aims to contribute to the citizen science discourse by offering researchers within the area practical suggestions to inform their practice (Section 1.1.3). The practical suggestions can enable citizen science researchers to be more inclusive, and to widen participation in citizen science.

7.4.1 Research training

The first suggestion from this project highlights the importance of capacity building. The data from the project of this thesis identifies how the co-researchers lacked certain research skills. Yet, by offering basic research training, the co-researchers were able to engage and indeed lead their own citizen science project with minimal support. The key influence on the capacity building programme within this project were the principles of inclusive research as discussed in Chapter 2.4.1. Walmsley & Johnson (2003) state that within inclusive research “people with learning disabilities need to be treated with respect by the research community” (p.16). Within this capacity building programme that meant creating an equitable environment where each person could discuss their views and influence the project. Furthermore, by accepting each person’s individual skills and creating opportunities for these to be shared within the group an inclusive capacity building programme can be created.

To successfully build a capacity building programme there are three considerations from this project:

1) Groundwork

Contemporary public engagement agendas are increasingly highlighting the importance of including ‘under-represented communities’ yet offer much less clear guidance for how to do this. To extend public engagement with science to a wider range of communities, I argue that we must first understand that these communities may not have the same levels of research literacy and confidence as the communities already engaged. This should not act as a conscious or unconscious rationale to exclude them. Citizen science organisers need to plan, within their research, to build capacity and confidence

of those they are engaging with. One suggestion of how to do this is to re-use (and adapt where necessary) the first phase of the project discussed within this thesis which used creative exercises to build confidence and identify capacity needs of the co-researchers (Section 4.2).

In this thesis, I have discussed how prior to the physical project I, as the researcher, engaged with the group in their own setting. This provided an understanding of their strengths and weaknesses. The co-researchers or participants within citizen science need to feel comfortable and confident in their engagement. In order to do this, meeting publics in their own settings where possible is suggested. Furthermore, the first phase of the project was framed as an introduction to certain research skills (discussions, lone and group working, creating topics of research), and is key to engagement with this community.

By creating physical or online resources for potential participant groups to engage with, laying the groundwork for research training, researchers can begin the process before directly engaging with the participant groups. Building strong foundations for engagement, and allowing time for relationships to emerge, will enable beneficial engagement for all parties involved later on in a citizen science study.

2) Creative engagement

During the final interviews of the project, the co-researchers highlighted how the creative aspects were their favourite part. The data also showed a much higher level of engagement during the creative tasks than the non-creative tasks. These tasks also gave the co-researchers time to build up their confidence and begin to think about research on their terms. The findings generated from these tasks informed the rest of the capacity building study and gave me, as the non-disabled researcher, the opportunity to gain knowledge on what capacities needed to be developed with the co-researchers.

The creative methods in this project were employed to offer the co-researchers the opportunity to develop their ideas of research and understand their identity in the scientific community. These activities provided the co-researchers the opportunity to discuss potential ideas for research and to work both independently and collectively.

I argue that citizen science researchers should consider employing creative methods in their practice, to offer the learning-disabled community an accessible way to engage with research training. By framing training through creative exercises, communities who may struggle with typical forms of engagement, have greater opportunities to engage and develop skills to enable further research.

Creative methods offer flexibility to both researchers and participants and can be used as a non-threatening way to begin discussions about future work. Whilst this thesis suggests that these methods work for engaging the learning-disabled community, more research needs to be done to understand whether these could be employed with different marginalised communities.

3) Scheduling

Groundwork and Creating Engagement have one key consideration in common: the need for sufficient time and careful scheduling. Research studies are often funded for a specific timeframe and the above considerations both take extra time to fulfil. As was suggested in Section 7.3.2, a key suggestion from this thesis is that funders adapt their remits and allow for broader, more flexible time frames to enable currently under-represented communities to be successfully engaged. Following inclusive research principles (Section 2.4.1) requires that research should be co-led and co-owned by the learning-disabled community. By involving this community in funding calls and decision making, and using their lived experiences, citizen science would have more potential to be inclusive. This is where further work needs to be done to understand ways in which these can be successfully employed within these time frames, such as remotely or in personal time away from the project.

7.4.2 Technology

Technology is become an increasingly popular way of engaging communities in science. Yet, there is a technology divide (Ragnedda & Muschert 2013; Warschauer, 2003; Seale, C et al., 2010; Selwyn, 2006) that excludes communities who may not have access or who are less technologically literate. In this thesis, I discussed how many of the co-researchers struggled with technology and the physical tasks had a higher level of engagement. Therefore, this thesis suggests that citizen science needs to provide non-technological approaches to engagement to reach those communities not currently engaged. To achieve this, I argue that there are four considerations for researchers.

1) Digital Accessibility

I argue that citizen science researchers should consider how they can make their planning more inclusive, by consulting the 'experts'. Within this project, there was a mix of technology literacy. From P4 who was confident in using technology to P8 who had not used a computer prior to this project. By consulting potential participant groups, citizen science researchers can ensure their approach to engagement through technology is accessible to those who are less literate and use the more technologically literate to support others. If I were to conduct this project again, I would explore the

technological literacies in the first phase with the co-researchers. This would then enable me to identify what capacity building is needed to ensure the co-researchers have all the tools to conduct their own citizen science study.

2) Creativity

The co-researchers identified how they enjoyed the creative tasks in the project the most. Furthermore, these tasks had the highest level of engagement throughout the project. Kara (2015) states how the role of technology within the creative process is yet to be scrutinised, and as technology is rapidly changing and adapting it can be hard for research to keep up. Yet, there are many methods which make use of creative technologies, such as photography, blogging and gaming.

I argue suggests that citizen science researchers consider how their technologies can be more creative in their engagement. This provides a more accessible approach whereby participants can engage in ways that may suit their needs better than traditional approaches such as writing.

3) Mixed modes: the use of offline resources

Technological literacy varies from person to person, independent of their community. Yet, there are communities in which technological literacy is often lower. These are frequently those communities who are currently 'under-represented' within public engagement activities. As the world moves to rely heavily on technology and the digital divide becomes larger, researchers are questioning how to access those potential participants with a lack of technology.

This project was conducted in a face-to-face environment, something which I acknowledge is not possible in larger scale projects. One thing which can be transferred however, is making use of the community groups who meet regularly. Often, these are supported by charities who have access to technology and can support their members in accessing it. Whilst this will not reach those on the outskirts of these communities, it can be a step in the right direction in creating a more inclusive citizen science. These groups can be engaged in the planning process by employing them to plan inclusive citizen science activities for the learning-disabled community.

The creation of offline resources by citizen science researchers could provide groups with the ability to engage in tasks in their own time and in supportive environments. In this project, offline paper resources were created to enable the co-researchers to engage without the direct need for a facilitator (see Appendix F)

It is only by identifying and seeking solutions to the digital divide that citizen science will be capable of including communities such as the learning-disabled community, with limited access to technology.

4) Easy read

Finally, it is key to any technology that it is in an easy read format. This enables the participants to understand and engage with the materials and platforms they need to use. Online software such as 'Photosymbols' (found at <https://www.photosymbols.com/>) is readily available to researchers and enables the learning-disabled community to engage with the materials. An example of easy read can be found in both the abstract of this thesis and Appendices C and D.

7.4.3 Group Work

The final suggestion for citizen science researchers, is to make use of the many local groups found around the country. In this project, I worked alongside a local self-advocacy charity to gain access to one of their groups. In the final interviews of the project, the co-researchers highlighted how working as part of a group was something they really enjoyed. The data suggests that the group environment allowed for the co-researchers to support one another and make use of everyone's individual skills.

A supported and structured approach to the group environment allowed the co-researchers to complete their own citizen science project from start to finish. This was, in part, down to the inclusive approach whereby the co-researchers were treated as experts in their fields as opposed to participants. I argue, that by making use of local groups across the country, citizen science can begin to become more inclusive and reach those communities the field has previously excluded.

Having discussed the practical suggestions from this project, I will now move on to discuss the theoretical suggestions.

7.5 Theoretical suggestions

The practical suggestions above offer citizen science researchers' ways in which to adapt their practices to include the learning-disabled community within their research. Section 7.6 provides a theoretical basis on which researchers can develop their inclusive practices. Through these theoretical suggestions I seek to influence the field of citizen science to make it more inclusive for the currently 'under-represented' communities.

7.5.1 ‘Inclusivity’ is key

I argue that we need to be more progressive in how citizen science is planned for, funded, enacted and reported. Progressive citizen science studies should focus on ‘involving a wider range of publics’ in scientific inquiry. The degree to which citizens are involved depends on the degree to which a project is predetermined by a set of researchers. Does a given project fit the needs and requirements of the participating citizens? If not, there is a danger that the citizens become de facto ‘tools’ used for the inquiry process.

Medvecky (2018) identifies how science communicators face ethical issues when sharing knowledge and choosing who to share it with (p.1395). I argue that science communicators must also consider the ethical implications of *how* they share their knowledge with publics. Citizen science needs to move from ‘involving’ publics to being genuinely ‘inclusive’ of publics. The co-researchers in this project demonstrated a wish to have their own voices reflected within research that impacted on them. They identified a capacity to advocate for not only the learning-disabled community but other communities as well as demonstrated in Chapter 5.4 and 5.5. The difference between ‘involving’ publics and being ‘inclusive’ can be found in the levels of participation required, allied with the support that is offered to facilitate meaningful engagement. ‘Involving’ publics suggests that the research is still owned by the lead researcher or institution. ‘Inclusive’ suggests that ownership is shared, as is the respect within the study. In Chapter 2.4.3, I introduced Arnstein’s (1969) ladder of participation. I highlighted how citizen science can sit anywhere on this ladder dependent upon the type of participation required for the project. There is a danger that, without genuine practices of inclusion, citizen science sits between ‘tokenism’ and ‘citizen power’, never quite sharing control with publics. I argue that, with careful planning, citizen power is achievable.

I argue that to include certain communities, such as the learning-disabled community, citizen science needs to involve publics in a greater number of the stages of the research process, committing to upstream engagement (Wilsdon & Willis, 2004). A key part of the co-researcher’s engagement in the project of this thesis, was their interest in the topic we were discussing. They were more likely to be interested if they themselves had set the agendas. Prior to beginning the project, the co-researchers were introduced to the plans for our work together. Furthermore, I consulted P11 who had worked with the group for 10 years. This assured me that I wasn’t making unfair or unreasonable assumptions, whilst still leaving space for plans to be adapted throughout the project. By moving from assumptions to consultations citizen science can ensure that it is inclusive of all, instead of targeting just a few.

7.5.2 Extending citizen science topics away from the ‘natural’ sciences

One reflection I made during this project, was how the topic choice made by the co-researchers was not like any I had seen in other citizen science projects. The outcome of the project was more ‘social’ than ‘scientific’. Yet, when researching for a definitive description as to what a citizen science topic should look like, I found Robinson et al.’s (2018) ten principles for citizen science. The second principle states:

“Citizen science projects have a genuine science outcome. For example, answering a research question or informing conservation action, management decisions or environmental policy”

Whilst this principle highlights how a citizen science project outcome could take many forms, it still focuses on the ‘science’ aspect. This thesis argues, that to include those currently excluded, citizen science needs to understand what it is these communities are interested in researching. Furthermore, citizen science needs to be more flexible on what science may mean to different communities.

7.5.3 Questioning what is ‘citizen science’?

Heigl et al. (2019) identified how citizen science does not have a generally recognized definition and how “in fact, the label CS (Citizen Science) is currently assigned to research activities either by project investigators themselves or by research funding agencies” (p. 8089). Whilst not attempting to offer a general definition for citizen science, I argue that, in its current form, citizen science is not inclusive. Much needs to be done by citizen science organisers to engage currently under-represented communities. Three key changes have been identified within this thesis to encourage a more inclusive citizen science: inclusive practices, research as a broader concept than ‘science’, and citizens as active participants. I will discuss each of these in more detail below.

Inclusive practices

I argue that the inclusive approach to citizen science in this thesis should neither be seen as distinctive from citizen science, nor inclusive research. Instead, the focus should be on combining the two fields to create a new form of public engagement which can truly fulfil the UKRI (2019) aim of “everyone in the UK [having] the opportunity to participate in research” (p.33). The principles of inclusive research (Chapter 2.4) can be applied to citizen science, by placing the responsibility of engagement on the researchers rather than currently disengaged communities. It is the citizen science researchers who

need to adapt their practice from ‘involving’ citizens to being genuinely inclusive of publics, not communities who need to adapt their way of engaging.

Citizens as active participants

The co-researchers in this project highlighted how the learning-disabled community have the capacity to create, conduct and discuss a citizen science project. They displayed how having an interest in the issue enhanced their engagement (Chapter 5.2). The co-researchers showed their capacity to conduct research and understand research processes (Chapter 5). They highlighted how support doesn’t have to be the sole responsibility of a researcher and how their own skills and experience can support others within the community (Chapter 6). The data collected within this project highlights how the learning-disabled community can conduct a citizen science project, suggesting that the reason this community is not engaging is the current approach citizen science takes to reaching this community. By engaging these under-represented communities as active participants, involved in more of the research process than is currently practiced within citizen science projects, facilitators can benefit from these communities’ skills and knowledge.

Research as a broader concept

Inclusive research is defined by Walmsley & Johnson (2003) through its focus on the interests of the learning-disabled community. Citizen science on the other hand is often focused on the interests of researchers and funders. How then, can we combine the two to create an inclusive citizen science? This thesis has moved away from focusing on the lived experiences of people with learning disabilities as is typically the subject of investigation in inclusive research projects (Section 2.4). Instead, it created a space for the co-researchers of this project to investigate into a topic unrelated to their disability. I argue that by using an inclusive approach and treating those engaging in citizen science as co-researchers, the citizen science field can begin to engage the under-represented communities and fulfil the UKRI’s (2019) aims of being for “everyone”. Through the collaboration of researchers and communities the field of citizen science can begin to expand its opportunities for engagement and create an inclusive environment whereby all parties involved can benefit from each other. By focusing less on creating new knowledge and instead acknowledging that the focus of citizen science research can be to disseminate current knowledge to new communities, citizen science organisers can begin to engage previously under-represented communities.

A key finding within this thesis, is that by sharing theories, principles and practices, citizen science organisers can benefit from the wealth of knowledge inclusive researchers have regarding engaging the learning-disabled community. This, I argue, highlights how by different communities opening up channels of communication they can share their learning and create opportunities for more inclusion actively involving different groups in research.

7.6 Key contextual factors

In Section 7.6, I will discuss the contextual factors of the project and how these impacted on the data collected.

One of the main contextual factors of the project was the time between the different phases of the data collection. There was a month between each session. This halted the momentum and occasionally the progress of the project. If tasks were not completed within the session this meant that there would be a month-long break before we could continue them. Whilst this was not ideal, the co-researchers addressed this issue by continuing work in their own time. This may have been continuing with a creative task at home or conducting some research. This conveyed their ownership over the project and their wish to be engaged. The month-long break also allowed for further work on my part, as I was able to reflexive in my approach to the group. By analysing the data in between each session, I could understand the groups needs better and work on how we could progress in the next session. Whilst this was a positive, the monthly visits also had an impact on the time the data collection took to complete. As the capacity building programme required time to teach new skills and practice them, the data collection took over a year to complete.

A key contextual factor to many studies is the gatekeepers, and more specifically the negotiation of access. This requires a more cooperative approach on the part of the researcher, being willing to not only adapt plans to meet the needs of the co-researchers, but also of the organisations. This creates opportunities for tensions which need to be carefully managed by the researcher, whilst ensuring the inclusivity of the work continues despite any tensions.

The main gatekeepers within this project were the people working at My Life My Choice. Firstly, I needed to get someone within the charity to see value in the work for the charity and the individuals. This was P11, the lead session worker for the self-advocacy groups. I was fortunate that she was very supportive of the project and planned to involve one of the groups she led in Banbury. Throughout the project, she was very supportive and involved herself as both a co-facilitator and co-

researcher. This co-operative approach highlighted the importance working as a group, instead of individuals within a research project. By understanding each group members individual skills and knowledge, the research was able to reflect the needs of each co-researcher.

One fortunate aspect of this project was that the group already had a safe space in which to meet. This was a space recognisable to them and somewhere they felt safe expressing their own opinions.

However, one limitation could have been that I was then entering that space as an ‘outsider’. To tackle this issue, I went into the group and joined in their activities three months prior to beginning my project. This allowed them the opportunity to get to know me and know me as someone else other than a ‘researcher’. This, I argue, is a key lesson for researchers wanting to conduct similar research. By entering the co-researcher’s space instead of the other way around, the researcher needs to be willing to adapt their role and take time out to build a rapport. This then can lead to a positive research environment, and aid in balancing the power distribution.

7.7 Co-researchers suggestions for citizen science researcher

In the final interviews for this project, the co-researchers were asked the question, ‘What advice would you give to researchers?’. Their answers are pictured below (Figure 18).

Figure 18 - Co-researcher's suggestions



The key message from the co-researchers on this project are that those organising citizen science activities should look at different ways of working. It is only by trying and either succeeding or failing alongside the community that the field will increase its participant base and more towards being truly inclusive.

This thesis' key contribution to knowledge is that the learning-disabled community can contribute to the citizen science discourse if citizen science is prepared to adapt its methods to include them. In order to do this, I suggest that citizen science requires to an inclusive citizen science approach.

This thesis aimed to answer the question: What support do people with learning disabilities require regarding their capacity to engage with citizen science? The support within the physical project used an inclusive approach to offer an environment in which the co-researchers could explore their capacities independently with support there should they require. To this end, a framework was developed to provide future researchers with the necessary skills to engage this excluded community.

Figure 19 - Inclusive Engagement



The 'inclusive engagement' framework has four parts:

1) Creativity – move away from 'traditional' methods of engagement. Creating more flexible approaches to participation may engage communities who are currently excluded due to their lack of literacy. Within this project the co-researchers identified how the creative aspects were the parts they enjoyed most. As discussed in Chapter 5.2 this was a key factor to engagement within this project and the creative tasks were often

those with the highest level of engagement from the co-researchers.

2) Considerations – consider what adaptations need to be made to practice to engage those currently excluded communities. Within this project a reflexive approach was adopted to ensure that the

research was suited to the co-researchers' needs (Chapter 4). This enabled them to engage in the research and take ownership over it.

3) Collaborations – collaborate with different community groups during planning stages to ensure that the research is inclusive in its nature. The co-researchers in this project showed clear capacity to engage in the planning process of the research. Furthermore, by engaging in this part of the process they were able to own the research and make it something which reflected their views instead of someone else's.

4) Communities – focus on what communities require from research alongside the scientific outcome. The process of inquiry can provide insights which are just as important as an outcome. The capacity building programme within this project identified the needs of each co-researcher. Through a reflexive approach it provided opportunities to learn new skills, and for the co-researchers to teach others within the group about skills they already possessed.

This thesis serves as a call to action for researchers involved in the planning and creation of citizen science projects. As research develops and funding bodies call for public engagement activities to include previously under-represented communities, we as researchers have a duty to adapt our practices. The suggestions listed above ensure that the learning-disabled community are not ignored, and have their voices included in the citizen science discourse. Furthermore, more research needs to be conducted to discover whether these suggestions can be used to engage more under-represented communities in scientific inquiry and broaden the science community.

References

- Abbot, S. & McConkey, R. (2015) *The barriers to social inclusion as perceived by people with intellectual disabilities*, Journal of Intellectual Disabilities, Vol. 10 (3), pp. 275-287
- Ahmet, A. (n.d.) *Creating and negotiating a principled online learning space*, Accessed on: 01/12/2020, Available at: <https://info.lse.ac.uk/staff/divisions/Eden-Centre/Resources-from-Eden/Creating-and-negotiating-a-principled-online-learning-space>
- Anderson, S. & Bigby, C. (2017) *Self-Advocacy as a Means to Positive Identities or People with Intellectual Disability: 'We Just Help Them, Be Them Really'*, Vol. 30, pp. 109-120
- Andrews, Tom. (2012) *What is Social Constructionism?*, Accessed on: 06/07/2021, Available at: <http://groundedtheoryreview.com/2012/06/01/what-is-social-constructionism/>
- Allgaier, J. (2010) Citizen Science, in Hornig, P, S (ed.) *Encyclopaedia of Science and Technology Communication*, SAGE publications, pp 130-132
- Archer, L. (2013-2017) *Science Capital Research*, Accessed on: 23/06/2020, Available at: <https://www.ucl.ac.uk/ioe/departments-and-centres/departments/education-practice-and-society/science-capital-research>
- Arnstein, S. (1969) *A Ladder of Citizen Participation*, Journal of the American Institute of Planners, Vol. 35 (4), p.216-224
- BARC workshop. (n.d) *Principled Space*, Accessed on: 01/12/2020, Available at: <https://barcworkshop.org/resources/principled-space/>
- Barr, O., McConkey, R. & McConaghie, J. (2003) *Views of People with Learning Difficulties about Current and Future Accommodation: The use of focus groups to promote discussion*, Disability & Society, Vol. 18 (5), pp. 577-597
- Barnes, C. (1992) *Qualitative research: Valuable or irrelevant?*, Disability, Handicap and Society, Vol. 7(2), pp. 115-124
- Barnes, C. & Mercer, G. (1997) *Exploring the Divide*, The Disability Press, Leeds
- Batson, C.D., Ahmad, N. & Tsang, J.A. (2002) *Four motives for community involvement*, Journal of Social Issues, Vol. 58 (3), p.429-445

- Batson, D. & Shaw, L. L. (1991) *Evidence for Altruism: Toward a Pluralism of Prosocial Motives*, Psychology Inquiry, Vol.2 (2), p.107-122
- Beart, S (2005), *'I won't think of myself as a learning disability. But I have': Social Identity and Self-Advocacy*, British Journal of Learning Disabilities, Vol 33, p.128-131
- Bell, P. & Mortimer, A. (2013) *Involving service users in an inclusive research project*, Learning Disability Practice, Vol. 16 (4), pp.28-30
- Bigby, C., Frawley, P & Ramcharan, P (2014) Conceptualizing Inclusive Research with People with Intellectual Disability, *Journal of Applied Research in Intellectual Disabilities*, Vol 27, p. 3-12
- Biggs, S. (2009) *New Media: The 'First Word' in Art?*, In: ed. Smith, H & Dean, R., Practice-led research, research-led practice in the creative arts, p.66-83. Edinburgh: Edinburgh University Press
- Bolton, E., Vorajee, Z. & Jones, K. (2005) *The Verismo of the Quotidian: A Biographic Narrative Interpretive Approach to Two Diverse Research Topics*, In: ed. Kelly, N., Horrocks, C., Milnes, K., Roberts, B. & Robinson, D. *Narrative, Memory & Everyday Life*, University of Huddersfield (p.9-17)
- Bonney, R., Cooper, C, B., Dickinson, J., Kelling, S., Phillips, T., Rosenberg, K, V, and Shirk, J. (2009) *Citizen Science: A Developing Tool for Expanding Science Knowledge and Scientific Literacy*, BioScience, Vol 59. (11), pp. 977-984
- Booth, T. & Booth, W. (1996) *Sounds of Silence: Narrative research with inarticulate subjects*, Disability & Society, Vol. 11 (1), pp.55-70
- Booth, T. & Booth, W. (2003) *In the frame: photovoice and mothers with learning difficulties*, Disability & Society, Vol.18 (4), pp. 431-422
- Bourke, L. (2009) *Reflections on doing participatory research in health: participation, method and power*, International Journal of Social Research Methodology, Vol 12 (5), pp. 457-474
- Boyask, R. & Vigurs, K. (2018) *Developing a methodology for public engagement with critical research*, Policy Futures in Education, Vol 16 (2), p.217-231
- Braun, V., and Clarke, V., (2006) Using thematic analysis in psychology, *Qualitative Research in Psychology*, Vol 3 (2), pp. 77-101, Available from: <http://eprints.uwe.ac.uk/11735>, Accessed on 08/01/20

- Braun, V. & Clarke, V. (2019) *Reflecting on reflexive thematic analysis*, Qualitative Research in Sport, Exercise and Health, Vol 11 (4), p. 589-597
- Brighton University (2018) *Visual Learning: Drawing*, Accessed on: 11/02/2019, Accessible at: <https://blogs.brighton.ac.uk/visuallearning/drawing/>
- Brossard, D., Lewenstein, B., and Bonney, R. (2005), *Scientific knowledge and attitude change: The impact of a citizen science project*, International Journal of Science Education, Vol 29. (9), pp. 1099-1121
- Brown, N. (2016) *Identity Boxes*, Nicole Brown, Accessible at: <https://www.nicole-brown.co.uk/identity-boxes/> , Accessed on: 18/01/2019
- Cambridge, P. & McCarthy, M. (2010) *User focus groups and Best Value in services for people with learning disabilities*, Health and Social Care in the Community, Vol. 9, pp.476-489
- Cappa, F; Laut, J; Porfiri, M. & Guistiano, L. (2018) *Bring them aboard: Rewarding participation in technology-mediated citizen science projects*, Computers in Human Behaviour, Vol 89, pg. 246-257
- Carr, J. E (2018) *How do People with Learning Disabilities Understand Citizen Inquiry?*, Available from: <http://oro.open.ac.uk/53815/>
- Chambers, D. (1983) *Stereotypic images of the scientist: the draw a scientist test*, Science Education, 67, pp. 255-265
- Clough, P. & Nutbrown, C. (2007) *A student's guide to methodology*, SAGE publications, London
- Cluley, V. (2016) *Using photovoice to include people with profound and multiple learning disabilities in inclusive research*, British Journal of Learning Disabilities, Vol. 45, pp. 39-46
- Cohen, L., Manion, L. & Morrison, K. (2000) *Research Methods in Education*, Routledge: London
- Cornwall, A. & Jewkes, R. (1996) *What is Participatory Research?*, Social Science and Medicine, Vol 41(12), pp. 1667 – 1676
- Costello, R. (2017) *A new century of (citizen) science*, Informal Learning Review, Vol 142, pp. 18-21
- CSA, (2018) *The power of citizen science* [online], Accessed on: 09/04/18, Available at: www.citizenscience.org

- Curtis, V. (2015(a)) Online citizen science projects: an exploration of motivation, contribution and participation, PhD Thesis, The Open University, Accessed on 05/09/19, Available at: <http://oro.open.ac.uk/42239/>
- Curtis, V. (b) (2015) Motivation to Participate in an Online Citizen Science Game: A Study of Foldit, *Science Communication*, Vol 37 (6), pg. 723-746
- Curtis, V., Holliman, R., Jones, A. C. & Scanlon, E. (2017) *Online citizen science: participation, motivation, and opportunities for informal learning*, in (Eds). Sharple, M., Herodotou, C. & Scanlon, E., *Citizen Inquiry: Synthesising Science and Inquiry Learning*, (pp.7 -24), Routledge.
- Daley, A. (2010) *Reflections on Reflexivity and Critical Reflection as Critical Research Practices*, *Affilia*, Vol. 25 (1), pp. 68-82
- Danieli, A. & Woodhams, C. (2005) *Emancipatory Research Methodology and Disability: A Critique*, *International Journal of Social Research Methodology*, Vol. 8(4), pp. 281-296
- Dawson, E. (2018) *Reimagining publics and (non) participation: Exploring exclusion from science communication through the experiences of low-income, minority ethnic groups*, *Public Understanding of Science*, Vol. 27 (7), p.772-786
- Department of Health. (2001) *Valuing People: A New Strategy for Learning Disability for the 21st Century* [online], Accessed on: 14/09/2020, Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/250877/5086.pdf
- Dibner, K. A. & Pandya, R. (2018) *Learning Through Citizen Science: Enhancing Opportunities by Design*, The National Academies Press, Washington DC, Accessed on 26/03/2020, Available at: https://www.ncbi.nlm.nih.gov/books/NBK535962/pdf/Bookshelf_NBK535962.pdf
- Dickinson, J. L., Bonney, R., Louv, R., and Fitzpatrick, W. J. (2012) *Citizen Science: Public Participation in Environmental Research*, Cornell University Press, USA
- Disabled People's International (1981) *Extract from 'Proceedings of the First World Congress'*, Singapore, 30 November – 4 December 1981, Accessed: 27/02/2018, <http://disability-studies.leeds.ac.uk/files/library/DPI-DPI81.pdf>
- Durant, J. (1994) *What is scientific literacy?*, *European Review*, Vol. 2 (1), p.83-89

- Durodie, B (2003) *Limitations of public dialogue in science and the rise of the new 'experts'*, Critical Review of International Social and Political Philosophy, Vol 6 (4), pp. 82-92
- Durrell, S. (2016) *"Welcome to the Real World" Inclusive Research with People with Learning Disabilities: A Doctoral Journey*, The Qualitative Report, 21(12), p.2308-2330
- Earle, S. (2003) *Disability and stigma: an unequal life.*, Speech & Language Therapy in Practice, p. 21-22, Accessed on: 25/09/2020, Available at:
https://oro.open.ac.uk/12660/1/Disability_and_Stigma.pdf
- ECSA e.g European Citizen Science Association (2015) *Ten principles of citizen science*, Available at:
https://ecsa.citizen-science.net/sites/default/files/ecsa_ten_principles_of_citizen_science.pdf, Last accessed: 30/05/2018
- Edwards, R. & Weller, S. (2012) *Shifting analytic ontology: using I-poems in qualitative longitudinal research*, Qualitative Research, Vol. 12 (2), pp.202-217
- Ellis, L. (2018) *Making decision together? Exploring the decision-making process in an inclusive research project*, Disability & Society, Vol. 33 (3), pp.464-476
- Embregts, P. J. C. M., Taminau, E. E., Heerkens, L., Schippers, A. P. & van Hove, G. (2018) *Collaboration in Inclusive Research: Competencies Considered Important for People With and Without Intellectual Disabilities*, Journal of Policy and Practice in Intellectual Disabilities, Vol. 15 (3), pp. 193-201
- Fenn, K. & Scior, K. (2019) *The psychological and social impact of self-advocacy group membership on people with intellectual disabilities: A literature review*, Journal of Applied Research for Intellectual Disabilities, Vol. 32, pp. 1349-1358
- Frankena, T. K., Naaldenberg, J., Bekkema, N., van Schrojecstein Lantman-de Valk, H., Cardol, M. & Leusnik, G. (2018(a)) *An exploration of the participation of people with intellectual disabilities in research – a structured interview survey*, Journal of Applied Research for Intellectual Disabilities, Vol. 31, pp. 942-947
- Frankena, T. K., Naaldenberg, J., Tobi, H., van der Crujsen, A., Jansen, H., van Schrojecstein Lantman-de Valk, H., Leunsink, G. & Cardol, M. (2018(b)) *A membership categorization analysis of roles, activities and relationships in inclusive research conducted by co-researchers with intellectual disabilities*, Journal of Applied Research in Intellectual Disabilities, Vol. 29, p.719-729

- Frawley, P. & Bigby, C. (2015) *Reflections on being a first generation self-advocate: Belonging, social connections and doing things that matter*, Journal of Intellectual & Developmental Disabilities, Vol. 40 (3), pp.254-264
- Freire, P. (1970) *Pedagogy of the Oppressed*, New York, Continuum
- Fullana, J., Pallisera, M., Catala, E. & Puyalto, C. (2017) *Evaluating a Research Training Programme for People with Intellectual Disabilities Participating in Inclusive Research: The Views of Participants*, Journal of Applied Research in Intellectual Disabilities, Vol. 30, pp.684-695
- Gillies, V. & Robinson, Y. (2012) *Developing creative research methods with challenging pupils*, International Journal of Social Research Methodology, Vol. 16 (2), pp. 161-173
- Godec, S., King, H. & Archer, L. (2017) *The Science Capital Teaching Approach: engaging students with science, promoting social justice*, London: University College London, Available at: <https://discovery.ucl.ac.uk/id/eprint/10080166/1/the-science-capital-teaching-approach-pack-for-teachers.pdf> Accessed on: 31/01/2021
- Goffman, E. (1963) *Stigma: Notes on the Management of Spoiled Identity*, Penguin Books, London
- Haklay, M. (2013) *Citizen Science and Volunteered Geographic Information: Overview and Typology of Participation*, in Sui, D., Elwood, S. & Goodchild, M. (ed.) *Crowdsourcing Geographic Knowledge – Volunteered Geographic Information (VGI) in Theory and Practice*, Springer: London, p. 105-124
- Hammersley, M. & Atkinson, P. (2007) *Ethnography: Principles in Practice*, 3rd ed., Routledge: London
- Hammersley, M. (2009) *Challenging relativism: the problem of assessment criteria*, Qualitative Inquiry, Vol 15 (1), p.3-29
- Hammersley, M. & Traianou, A. (2012) *Ethics in qualitative research: controversies and contexts*, SAGE Publications Ltd
- Hammersley, M. (2016) *Reading Ethnographic Research* (2nd ed.), Routledge: OXON
- Havens, K. & Henderson, S. (2013) *Citizen Science takes root*, American Scientist, Vol. 10(5), pp. 378-385
- Heigl, F., Kieslinger, B., Paul, K. T., Uhlik, D. & Dorler, D. (2019) *Opinion: Toward an international definition of citizen science*, Proc. Natl. Acad. Sci. U.S.A, Vol. 116 (17), pp. 8089-8092

Herodotou, C., Aristeidou, M., Sharples, M. & Scanlon, E. (2018) *Designing citizen science tools for learning: lessons learnt from the iterative development of nQuire*. Research and Practice in Technology Enhanced Learning, Vol. 13 (4), Available at: <http://oro.open.ac.uk/55067/> Accessed on: 01/02/2021

Higgins, K. (2015) *On Criticisms of Citizen Science* [online], Accessed on: 26/03/2020, Available at: <https://blogs.qub.ac.uk/qubio/2015/08/14/on-criticisms-of-citizen-science/>

Hingley-Jones, H (2013), *Emotion and relatedness as aspects of the identities of adolescents with severe learning disabilities: contributions from 'practice-near' social work research*, Child and Family Social Work, Vol 18, p.458-466

Holland, K (2011), *Factsheet: Learning Disabilities*, [online], Accessed on: 15/11/2018, Available at: file:///userdata/documents8/jec748/Downloads/Learning_Disabilities_11.pdf

Holliman, R. & Curtis, V. (2015) Online Media, in Gunstone, R (ed.) *Encyclopedia of Science Education*. Springer Reference, pp. 718-25. Available from: http://link.springer.com/referenceworkentry/10.1007/978-94-007-2150-0_53 Accessed on: 26/04/2017

Holliman, R. (2017) *Supporting excellence in engaged research*, Journal of Science Communication, Vol. 16(5) p. 1–10

Holliman, R. (2019). '[Promoting epistemic justice through knowledge exchange](#)'. Keynote address at the Research and Knowledge Exchange Conference, University of East London, 27 June.

Holliman, R. and Jensen, E. (2016) *Norms and values in UK science engagement practice*, Journal of Science Education, Part B: Communication and Public Engagement, Vol 6 (1), pp. 68-88

Holloway, I.& Todres, L. (2003) *The status of method: flexibility, consistency and coherence*, Qualitative Research, Vol. 3 (3), pp. 345-357

House of Commons, Science & Technology Committee (2017a) *Science Communication and Engagement*, House of Commons, Available from: <https://www.publications.parliament.uk/pa/cm201617/cmselect/cmsctech/162/162.pdf> Accessed on: 07/01/20

House of Commons, Science & Technology Committee (2017b) *Science Communication and Engagement*, House of Commons, Available from:

<https://publications.parliament.uk/pa/cm201719/cmselect/cmsctech/319/319.pdf> Accessed on: 07/01/20

House of Lords Select Committee Report (2000) *Science and Society*, House of Lords, Available from: <https://publications.parliament.uk/pa/ld199900/ldselect/ldsctech/38/3801.htm> Accessed on: 21/10/2020

Idiots Act (1886), *Journal of Mental Science*, Vol.33 (141), p.103-108

Inglis, P. & Cook, T. (2011) *Ten top tips for effectively involving people with a learning disability in research*, *Journal of Learning Disabilities and Offending Behaviour*, Vol 2 (2), p. 98-104

Irwin, A. (1995), *Citizen Science: A study of people, expertise, and sustainable development* (Environment and society), London; New York: Routledge

Irwin, A. (2008). Risk, science and public communication: Third order thinking about scientific culture. In M. Bucchi & B. Trench (Eds.), *Public communication of science and technology handbook* (pp. 199–212). London: Routledge.

Irwin, A. & Wynne, B. (1996) *Misunderstanding Science*, Cambridge University Press

Jellema, P., Annemans, M., & Heylighen, A. (2019) *Researching and Designing Health Care Environments: A Systemized Review of Creative Research Methods*, *Qualitative Health Research*, Vol. 29 (2), og. 290-300

Jennett, C., Kloetzer, L., Schneider, D., Iacovides, I., Cox, A., Gold, M., Fuchs, M., Eveleigh, A., Methieu, K., Ajani, Z. & Talsi, Y. (2016) *Motivations, learning and creativity in online citizen science*, *Journal of Science Communication*, Vol 15 (3), pg.1-23

Jones, M, G., Childers, G., Andre, J., Corin, N, E. & Hite, P. (2018) *Citizen scientists and non-citizen scientist hobbyist: motivation, benefits and influences*, *International Journal of Science Education*, Part B, Vol 8 (4), pg. 287-306

Kara, H. (2015) *Creative Research Methods in the Social Sciences*, Policy Press, Bristol

Kellett, M. (2010) *Small Shoes, Big Steps! Empowering Children as Active Researchers*, *American Journal of Community Psychology*, Vol. 46 (1-2), p. 195-203

Kennedy, E, B. (2016) *When Citizen Science meets Science Policy*, in ed. Kennedy, E. B. & Cavalier, D. (2016) *The Rightful Place of Science: Citizen Science*, Consortium for Science, Policy and Outcomes, Tempe, AZ and Washington, D.C

- Kennedy, L. & Brewer, G. (2014) *Creative methodologies to enhance communication*, British Journal of Learning Disabilities, Vol. 44, pp. 35-42
- Kiernan, C. (1999) *Participation in Research by People with Learning Disability: Origins and Issues*, British Journal of Learning Disabilities, Vol. 27, pp.43-47
- Land-Zastra, A. M., Devilee, J. L. A., Snik, F., Buurmeyer, F. & Vander Broek, J. M. (2016) *Citizen science on a smartphone: Participants motivations and learning*, Public understanding of science, Vol 25(1), pg.45-60
- Lincoln, Y.S. & Guba. E. G. (1985) *Naturalistic Inquiry*, Beverly Hills, Calif: Sage Publications
- Maalouf, A. (2000) *On Identity*, Vintage
- Mahony, N. (2015) *Designing Public-Centric Forms of Public Engagement with Research*, The Open University, Milton Keynes, Accessed on: 07/12/2020, Available at:
<http://oro.open.ac.uk/42551/7/Holliman.pdf>
- Medvecky, F. (2018) *Fairness in Knowing: Science Communication and Epistemic Justice*, Science and engineering ethics, Vol. 24 (5), p.1393-1408
- Medvecky, F. & Leach, J. (2017) *The ethics of science communication*, Journal of Science Communication, Vol.16 (4), E. Accessed on: 11/12/2020, Available at:
https://jcom.sissa.it/sites/default/files/documents/JCOM_1604_2017_E.pdf
- Miller-Rushing, A., Primack, R. and Bonney, R. (2012) *The history of public participation in ecological research*, Frontiers in Ecology and the Environment, Vol 10 (6), pp.285-290
- Moncrieffe, J. & Eyben, R. (2013) *The Power of Labelling: How People are Categorized and Why it Matters*, London: Routledge
- Morris, J. (2005) *Citizenship and Disabled People: A Scoping Paper Prepared for the Disability Rights Commission*, Disability Rights Commission, London.
- Mueller, M., Tippins, D. & Bryan, L. (2011) *The Future of Citizen Science*, Democracy & Education, Vol 20 (1), p.1-12
- My Life My Choice. (n.d) *What is self-advocacy*, Accessed on 15/01/2020, Available at:
<https://www.mylifemychoice.org.uk/pages/9-what-is-self-advocacy>
- Nind, M., (2008) *Conducting qualitative research with people with learning, communication and other disabilities: Methodological challenges*, National Centre for Research Methods
- Nind, M. & Vinha, H. (2012) *Doing research inclusively: doing research well?* Research report
- Nind, M. (2014) *What is inclusive research?*, London: Bloomsbury Academic

- Nind, M. & Vinha, H. (2014a) *Creative interactions with data: using visual and metaphorical devices in repeated focus groups*, Qualitative Research, Vol. 16 (1), pp. 9-26
- Nind, M., & Vinha, H. (2014b) *Doing research inclusively: bridges to multiple possibilities in inclusive research*, British Journal of Learning Disabilities, Vol 42, pp. 102-109
- Nind, M., Chapman, R., Seale, J. & Tilley, L. (2016) *The Conundrum of Training and Capacity Building for People with Learning Disabilities Doing Research*, Journal of Applied Research in Intellectual Disabilities, Vol. 29, pp. 542-551
- Nind, M. (2017) *The practical wisdom of inclusive research*, Qualitative research, Vol 17 (3), pp. 278-288
- Noel, L. A. (2016) *Promoting an emancipatory research paradigm in Design Education and Practice*, Presented at: Research Design Society 50th Anniversary Conference, Brighton, 27-30th June 2016
- Nowell, L. S., Norris, J. M., White, D. E. & Moules, N. J. (2017) *Thematic Analysis: Striving to Meet the Trustworthiness Criteria*, International Journal of Qualitative Methods, Vol. 16, p.1-13
- Nowotny, H., Scott, P. and Gibbons, M. (2003) ‘*Mode 2*’ *Revisited: The New Production of Knowledge*’, Minerva, Vol. 41, p. 179-194
- Ollerton, J. (2012) *IPAR, an inclusive disability research methodology with accessible analytical tools*, International Practice Development Journal, Vol. 2 (2-3)
- Oliver, M. (1990) *The Politics of Disablement*, Basingstoke: Macmillan
- OpenScientist, (2018) *OpenScientist*, [online] Accessed on: 09/04/18, Available at: <http://www.openscientist.org/>
- Osborne, J. (2010) *Science for Citizenship*, in: Osborne, J. and Monk, M. *Good Practice in Science Teaching: what research has to say*. Buckingham: Open University Press
- Pandya, R. E. (2012) *A framework for engaging diverse communities in citizen science in the US*, Frontiers Ecological Environment, Vol 10 (6) p. 314-317
- Potter, S. (2006) *Doing Postgraduate Research*, Open University Press, 2nd Edition
- Puyalto, C., Pallisera, M., Fullana, J. & Villa, M. (2016) *Doing Research Together: A Study on the Views of Advisors with Intellectual Disabilities and Non-Disabled Researchers Collaborating in Research*, Journal of Applied Research in Intellectual Disabilities, Vol. 29, pp. 146-159

- Ragnedda, M. & Mushcert, M. (2013) *The Digital Divide: The Internet and Social Inequality in International Perspective*, Routledge: New York
- Reed, M. S. (2016) *The Research Impact Handbook*, Fast Track Impact, Aberdeenshire
- Reilly, P. (2017) *Creative approaches to teaching graduate research methods workshops*, Nordic Journal of Information Literacy in Higher Education, Vol. 9 (1), pg. 21-36
- Richards, M., Lawthom, R. & Runswick-Cole, K. (2019) *Community-based arts research for people with learning disabilities: challenging misconceptions about learning disabilities*, Disability & Society, Vol. 34 (2) p. 204-227
- Riches, T. N., O'Brien, P. M. & The CDS Inclusive Research Network. (2017) *Togetherness, teamwork and challenges: "Reflections on building an inclusive research network"*, Journal of Learning Disabilities, Vol. 45, pp.274-281
- Rix, B. (2006) *All about us! The story of people with a learning disability and Mencap*, Mencap
- Robinson, L.D, Cawthray, J. D, West, S. E., Bonn, A. & Ansine, J. (2018) *Ten principles of citizen science: Innovation in Open Science, Society and Policy*, In: Hecker, S., Haklay, M., Bowser, A., Makuch, Z., Vogel, J. and Bonn, A. (eds.) *Citizen Science – Innovation in Open Science, Society and Policy*, pp. 27-40, UCL Press: London
- Rotman, D, Hammock, J, Preece, J, Hansen, D, Boston, C, Bowser, A and He, Y. (2014) *Motivations affecting initial and long-term participation in citizen science projects in three countries*, In: iConference 2014 Proceedings, p.110–124.
- Royal Commission (1908), *Care and Control of the Feeble-minded*. London: HMSO
- Ruiz-Mallen, I., Riboli-Sasco, L., Ribault, C., Heras, M., Laguna, D., and Perie, L. (2016) *Citizen Science: Toward Transformative Learning*, Science Communication, Vol 38 (4), pp. 523-534
- STFC. (2016) *Inspiring and Involving: Public Engagement Strategy 2016-2021* [online], Accessed on: 15/09/2020, Available at: <https://stfc.ukri.org/files/corporate-publications/stfc-public-engagement-strategy/>
- Sanger, J. (1994) *Seven types of Creativity: Looking for Insights in Data Analysis*, British Educational Research Journal, Vol. 20 (2), pp. 175-185

- Schofield, J. W. (2007) Increasing the generalizability of qualitative research, in Hammersley, M. (ed.) *Educational Research and Evidence-based Practice*, (p.181-203), Sage Publications, London
- Schwartz, A. E., Kramer, J. M., Cohn, E. S. & McDonald, K. E. (2020) “*That Felt Like Real Engagement*”: *Fostering and Maintaining Inclusive Research Collaborations with Individuals with Intellectual Disability*, *Qualitative Health Research*, Vol 30 (2), p. 236-249
- Schutz, A. (1962) *Collected Papers 1: The Problem of Social Reality.*, The Hague: Martinus Nijhof
- Seale, J.K. (2007) *Strategies for supporting the online publishing activities of adults with learning difficulties*, *Disability & Society*, Vol. 22 (2), p.173-186
- Seale, C., Charteris-Black, J., Macfarlane, A. & McPherson, A. (2010) *Interviews and Internet Forums: A comparison of two sources of qualitative data*, *Qualitative Health Research*, Vol. 20, pp. 595-606
- Seale, J., Nind, M., & Parsons, S. (2014) *Inclusive research in education: Contributions to method and debate*, *International Journal of Research & Method in Education*, Vol 37 (4), pp. 347-356
- Seale, J., Nind, M., Tilley, L. & Chapman, R. (2016) *Negotiating a third space for participatory research with people with learning disabilities: an examination of boundaries and spatial practices*, *Innovation: The European Journal of Social Science Research*, Vol. 28 (4), pp.483-497
- Seale, J. & Chadwick, D. (2017) *How does risk mediate the ability of adolescents and adults with intellectual developmental disabilities to live a normal life by using the Internet*, *Cyberpsychology: Journal of Psychosocial Research on Cyberspace*, Vol. 11 (1), Available at:
https://wlv.openrepository.com/bitstream/handle/2436/620528/SealeandChadwick_How%20does%20risk%20mediate%20the%20ability%20of%20adolescents%20and%20adults%20with%20intellectual%20and%20developmental%20disabilities%20to%20live%20a%20normal%20life%20by%20using%20the%20Internet_Cyberpsych.pdf?sequence=1&isAllowed=y Accessed on: 21/10/2020
- Selin, C., Campbell Rawlings, K., Ridder-Vignone, K de., Sadowski, J., Allende, C. A., Gano, G., Davies, S. R. & Guston, D, H. (2017) *Experiments in engagement: Designing public engagement with science and technology for capacity building*, *Public Understanding of Science*, Vol 26 (6), p.634-649
- Selwyn, N. (2006) *Digital Division or digital decision? A study of non-users and low-users of computers*, *Poetics*, Vol 34 (4-5), pp. 273-292

- Silvertown, J (2009) *A new dawn for Citizen Science*, Trends in Ecology & Evolution, Vol. 24(9), pp. 467-471
- Sinfield, S. (2018) *Developing creative practice from induction and assessment*, Creative Academic, Accessed on: 11/02/2019, Accessible at: http://www.creativeacademic.uk/uploads/1/3/5/4/13542890/cam_10_march18_v1.pdf
- Strnadova, I; Cumming T. M; Knox M; Parmenter T. & Welcome to Our Class Research Group (2014) *Building an inclusive research team: the importance of team building and skills training*, Journal of Applied Research in Intellectual Disability, Vol 27, p.13-22
- Strnadova, I., Walmsley, J., Johnson, K. & Cumming, T. M. (2016) *Diverse faces of inclusive research: reflecting on three research studies*, Scandinavian Journal of Disability Research, Vol. 18 (1), pp. 52-64
- Strnadova, I; Johnson, K & Walmsley, J (2018), “*but if you’re afraid of things, how are you meant to belong?*” *What belonging means to people with intellectual disabilities*, Journal of Applied Research and Intellectual Disabilities, Vol 31, p.1091-1102
- Tilly, L. (2015), *Being researchers for the first time: reflections on the development of an inclusive research group*, British Journal of Learning Disabilities, Vol 43, p.121-127
- Toerpe, K., (2013) *The Rise of Citizen Science*, The Futurist
- Thomas, D & Woods, H (2003), *Working with People with Learning Disabilities: Theory and Practice*, Jessica Kingsley, London
- Tuffrey-Wijne, I. & Butler, G. (2010) *Co-researching with people with learning disabilities: an experience of involvement in qualitative data analysis*, Health Expectations, Vol. 13, pp.174-184
- UKRI (2019) *Delivery Plan 2019*, Accessed on: 07/10/2020, Available at: <https://www.ukri.org/about-us/delivery-plans/>
- Vetter, J. (2011) *Introduction: Lay Participation in the History of Scientific Observation*, Science in Context, Vol 24(2), pp.127-141
- Walmsley, J. (2004) *Inclusive learning disability research: the (non-disabled) researcher’s role*, British Journal of Learning Disabilities, Vol. 32 (2), p.65-71

- Walmsley, J. & Johnson, K. (2003) *Inclusive research with people with learning disabilities: past, present and futures*. London, Jessica Kingsley.
- Walmsley, J. & The Central England People First History Project Team. (2014) *Telling the History of Self-Advocacy: A Challenge for Inclusive Research*, Journal of Applied Research in Intellectual Disabilities, Vol. 27, pp.34-43
- Warschauer, M. (2003) *Technology and Social Inclusion: Rethinking the Digital Divide*, MIT Press, London
- Wehmeyer, M. L., (2014) *Promoting Self-Determination in Students with Developmental Disabilities*, Guildford Publications
- Wellcome Trust/MORI. (2001) *The role of scientists in public debate: Full Report*. London: The Wellcome Trust
- West, S.E. & Patemen, R. (2015) *Recruiting and Retaining Participants in Citizen Science: What can be Learned from the Volunteering Literature?*, Citizen Science Theory and Practice, Vol. 1 (2), p.15
- Williams, R. (1989) *Culture & Society: Essential Writings*, SAGE: London
- Wilkinson, S. (2005) *What's so special about being 'special'?*, Learning Disability Practice, Vol. 8 (10), pp. 30-31
- Wilsdon, J. & Willis, R. (2004) *See-through Science – Why public engagement needs to move upstream*, Demos, Accessed on: 25/09/2020, Available at: <http://www.demos.co.uk/files/Seethroughsciencefinal.pdf?1240939425>
- Woelders, S., Abma, T., Visser, T., & Schipper, K. (2015) *The power of difference in inclusive research*, Disability and Society, Vol 30 (4), pp. 528-542
- Yacoub, E. & Hall, I. (2006) *The sexual lives of men with mild learning disability: a qualitative study*, British Journal of Learning Disabilities, Vol. 37, p.5-11




Appendix A – Banbury My Life My Choice ‘Trifold’ Leaflet

At what age does a cat or dog get vaccinated?



- Puppies are typically vaccinated at 8-10 weeks or as early as 4-6 weeks and must have a booster at 6-12 months
- Kittens have 2 sets of vaccinations, one at nine weeks and one at 3 months old and kittens must have a booster every 12 months
- Until your kitten is fully vaccinated and neutered you must keep them indoors

How to deal with cat or dog that has anxiety?



Buy a calming spray and ask about medication from the vets. Find a safe space for them to hide. Give plenty of cuddles and strokes



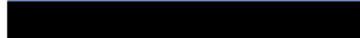
Thank you for reading and we hope you found it helpful!



How to look after cats and dogs



Banbury My Life My Choice Self-Advocacy Group





Who are we and what is this leaflet about?

This project was created by the My Life My Choice Banbury Group:



We have done a citizen science project, where we did some research through sending surveys to vets.

This is what we found out.

How to train a cat or dog

Give them a treat that's one way of praising them. You can also give them a pat or a stroke.

If a dog sits when it is told, give it a reward

What to do if your cat or dog gets bitten

Take it to the vets they will dean it and give the pet medication

How to stop a cat or a dog from being mistreated

If you see an animal being hurt phone the police or the RSPCA or 999

Be prepared to explain:

- Description of person
- Description of animal
- Your name and number



How to feed a cat or a dog

Make sure you have plenty of food for your pet. Stick to the times you feed them. If they're on a diet, stick to it (less treats). Leave them in peace to eat their food.

When do you get a cat or dog neutered?

Depends on the breed of the dog. Discuss with your vet what's right for your dog.

Cats can be neutered from around 4 months after their primary vaccinations Some vets recommend spaying at 5-6 months and it is safe to get older cats neutered.

What to look for if your cat or dog is poisoned :

- Vomiting
- Drooling
- Shock or collapse
- Change in behavior
- Weakness or tiredness

Appendix B: HREC approval HREC/2958/Carr

Project title: Can an inclusive approach enable people with learning disabilities to identify their capacity needs when engaging with citizen science?

Date application submitted: 22/08/2018

HREC response date: 05/11/2018

This message confirms that the research protocol for the above-named research project, as submitted for ethics review, has been given a favourable opinion on behalf of The Open University Human Research Ethics Committee.

As part of your favourable opinion, it is essential that you are aware of and comply with the following:

1. You are responsible for notifying the HREC immediately of any information received by you, or of which you become aware which would cast doubt on, or alter, information in your original application, in order to ensure your continued safety and the good conduct of the research.
2. It is essential that you contact the HREC with any proposed amendments to your research, for example - a change in location or participants. HREC agreement needs to be in place before any changes are implemented, except only in cases of emergency when the welfare of the participant or researcher is or may be affected.
3. Your HREC reference number has to be included in any publicity or correspondence related to your research, e.g. when seeking participants or advertising your research, so it is clear that it has been agreed by the HREC and adheres to OU ethics review processes.
4. Researchers should have discussed any project-related risks with their Line Manager and/or Supervisor, to ensure that all the relevant checks have been made and permissions are in place, prior to a project commencing, for example compliance with IT security and Data protection regulations.
5. Researchers need to have read and adhere to relevant OU policies and guidance, in particular the Ethics Principles for Research involving Human Participants and the Code of Practice for Research - <http://www.open.ac.uk/research/ethics/>
6. The Open University's research ethics review procedures are fully compliant with the majority of research council, professional organisations and grant awarding bodies research ethics guidelines. Where required, this message is evidence of OU HREC support and can be included in an external research ethics review application. The HREC should be sent a copy of any external applications, and their outcome, so we have a full ethics review record.
7. At the end of your project you are required to assess your research for ethics related issues and/or any major changes. Where these have occurred you will need to provide the Committee with a HREC final report to reflect how these were dealt with using the template on the research ethics website

- <http://www.open.ac.uk/research/ethics/human-research/full-review-process> (HREC Final Report form)

Appendix C: Consent form



How do people with learning disabilities do citizen science?

NAME

Please circle your choice:

If you agree: Yes



If you don't agree: No



1. I want to take part in the project



Yes



No

2. The project was explained to me



Yes



No

3. I was informed that I can say I don't want to join in at any point, and take back my consent for this study



Yes



No

4. I understand all my information will be kept safe



Yes



No

5. I can be audio-recorded or photographed (this will not affect your ability to take part in the project) – any images of you will not be altered



Yes



No

6. My pictures and ideas from the Citizen Science Project can be used for education or research and publication (this will not affect your ability to take part in the project)



Yes



No

You can say NO at any time

7. I have received and understood the information sheet



Yes



No

You can say NO at any time

You may withdraw your consent at any point up until the final session. If you choose to withdraw your consent then any data held involving you will not be used in the analysis or publishing of the findings.

Privacy Notice:

Any data collected from this study will be stored on an Open University laptop and a safe USB. Before anything is written up all data will be made so that you cannot be recognised, and will only be shared between myself and my supervisors. Your data will be kept secure and will only be used for my studies and any writing after/during this.

I understand the above notice and give permission for any data collected from the study to be used in this manner:



Yes



No

You can say NO at any time

I give permission to the Open University to share and use my words and thoughts. This is my copyright.

I agree to give my copyright to the Open University. They will not use my copyright for profit.

Signed

Date

Open University Postgraduate Student

Jessica Carr

Jess.Carr@open.ac.uk





Institute of Educational Technology

The Open University
Walton Hall
Milton Keynes
United Kingdom
MK7 6AA

Can people with learning disabilities be citizen scientists?

I want to work with people with learning disabilities to find out where they need help to do **citizen science**. I will use this information to try and improve access to future citizen science projects.

Citizen Science is where members of the public, like yourself, become ‘co-researchers’, choosing what to ‘research’, collecting ‘data’ about your selected topic and analysing it (Birdwatch by RSPB)

What is a co-researcher? Being a co-researcher means that you will be leading a research project alongside other co-researchers. You will be supported in this and will be able to help make decisions about the project.

What is research? Research is where people find a question and investigate it to get the answer.

What is data? Data is information that we collect during the study. This might be items that you make, information that you collect, or notes that I make during the sessions. Any data will be shared with you.



We need to give teachers, researchers and scientists good advice about how to help you and others conduct citizen science projects independently.



I will write a long report about the research called a thesis, alongside other smaller documents. This will be published alongside data from the study. Your name and personal details will not be included in any publications.

Why should you get involved?

You may learn something new about a topic you're interested in.

You'll develop skills in conducting research.

You will be **co-researchers**, helping improve citizen science for other people with learning disabilities.

How will the research be done?

The research will take place over a period of 10 months, with one hour sessions every other week.

There will be 4 phases:

Phase 1 – This phase will be where we work out what research is and decide what we want to research.

Phase 2 – This phase will be where we decide how we're going to do our research.

Phase 3 – This phase will be where we do our research and work out what we have found from it. Then we will decide how we tell people about it.

Phase 4 – Throughout the first three phases we will have chances to explore what we struggled with or found the easiest. Then we will show off our work!

During the process we will be working together to collect data and study it, talking about anything we think is interesting.

Over the course of the study you will be asked to draw pictures, write or record yourselves talking about what you're thinking.



I will be recording the sessions, asking you questions and writing notes when I can, to make sure I have all of your thoughts and opinions. I will share these with you and you can say you would not like to be recorded. In which case anything you say will not be used.



During the sessions you may be photographed and/or videoed. These will be used to support the notes and recordings. If you do not want your picture taken you can say this on the consent form. You can still take part in the study.

After the study, I will write a large book about what we have found, alongside other smaller documents available to you and other members of the public. You will be able to see these, and I will come back to talk to you about the research for advice when writing my book.

Safeguarding:

Any data held will be **anonymised** to remove names and any words and/or phrases which could identify you. Any photographs will not be linked to names, but will be published without alterations.

Withdrawal is when you want to take away your **consent** to be part of the study. This includes any data that you might be part of.

Consent is you agreeing to do something, such as taking part in the study or your thoughts being used as data. You can withdraw at any time during the study.

Privacy Notice:

Any data collected from this study will be stored on an Open University laptop and safe storage devices. Before anything is written up all data will be made so that you cannot be recognised, and will only be shared between myself and my supervisors. Your data will be kept secure and will only be used for my studies and any writing after/during this.

If you want more information about joining the Citizen Science Project you can contact Jessica Carr at: jess.carr@open.ac.uk

Or if you are unhappy about how Jessica Carr is running the study, you can contact her supervisor Jane Seale at:

jane.seale@open.ac.uk





Institute of Educational Technology

The Open University
Walton Hall
Milton Keynes
United Kingdom
MK7 6AA

Can people with learning disabilities be citizen scientists?

Parents and Guardians Information sheet – My Life My Choice

What's it all about?

The aim of the project is to explore what support people with learning disabilities require in regard to their capacity to engage with **citizen science** through an **inclusive approach**.

Citizen Science is a crowd-sourced form of inquiry where members of the general public collect and analyse data using the scientific process. An example of how citizen science works in practice is illustrated in the following short video: <https://youtu.be/1OI4IFPCjxw>. (The video is just over five minutes long.)

Inclusive Research Methods are where the research is done with participants as co-researchers. Those contributing to this study will be treated as partners in the research. The idea that the researcher knows best is challenged, and the participants are the ones making decisions about the research.

The results from the project will be used to support the design of future citizen science initiatives at the Open University and beyond. Through this research we will offer greater opportunities for people with learning disabilities to participate in citizen science projects that have meaning and relevance to them.

What am I asking the participants to do?

This study will follow a four phase process:

- 1) **Proposing a research topic;**
- 2) **Designing a process to investigate the selected topic;**
- 3) **Managing, analysing and sharing information gathered to explore the topic;**
- 4) **Reflections on capacity; what would have helped to support the participants through the first three phases.**

The participants will be asked to design and undertake their own research project using the Open University's online platform 'nQuire' [<http://www.nquire-it.org/#/home>]. nQuire is the platform shown in the short video above. This platform facilitates the collection and analysis of data by groups of people sharing similar scientific interests. nQuire will support the first three phases of the project.

Phase 4 will run throughout the first three phases. Through a mixture of **observation, facilitated group discussions** and **creative research methods**, I will explore participant interactions with the project, and opinions on how they understand it within the context of their lives will be documented. All participants in the project will be anonymised in the write up.

The project will run for a period of 10 months.

I will **observe** the participants whilst they are doing the citizen science project and provide any support they need to complete the project. This will help me understand how much support may be required to enable participation in a project such as this, and where citizen science may need to be more accessible to this community. I will support my observations by taking **fieldnotes** which are a form of research based note-taking. Furthermore, I will take photographs and/or videos during the study. The participants can choose to not have their picture taken and they will still be able to take part in the study.

Facilitated group discussions will create a safe and supportive space in which the participants can be open about their feelings. The groups will be audio recorded so that I have an accurate account, ensuring the participants views and opinions are reflected in my work.

Creative research methods will offer an alternative way for the participants to engage in the study. These will range from collages, to photography and will allow each participant to engage no matter what their disability.

Once the study is completed I will analyse the data and write it up into a **thesis** (80,000 word document, detailing the study – used for examination purposes). I will meet the participants and any interested parents/guardians to discuss the study and the thesis.

Safeguarding

The study will ask the participants to design and run their own study. Whilst I do not anticipate that the subject matter of these studies will be of a sensitive nature, I will ensure to refer to the My Life My Choice safeguarding procedures if any participants get upset from the study. In any publications the participants will be fully anonymised, with any identifying features being removed from the data.

Who am I?

Before embarking on my PhD, I worked for Oxfordshire based charity Yellow Submarine running their Witney Social Enterprise Café. I asked My Life My Choice to collaborate on this project because of the self-advocacy work I have seen, and the opportunities they offer to their members. I believe that all people deserve to be given the same opportunities, and I believe this project will provide knowledge to help towards this progress.

Who is supporting me to do the research?

At university I have supervisors to guide me in doing this research. My lead supervisor Professor Jane Seale has a long career with inclusive research. Her research focuses on the role that technologies play in the lives of people with learning disabilities and the factors that influence or sustain the digital exclusion of disabled learners. Her recent work has also focused on how the inclusive practices of teachers and support workers might be enhanced through the development of 'positive risk taking'.



Furthermore, I have been working alongside Ruth Shaw-Williams who co-ordinates the self-advocacy groups at My Life My Choice. She has been integral in ensuring the study best suits the participants interests.

Please Remember:

- It will be their decision to take part.
- We won't require reasons for not taking part.

If unsure about any of the details above please contact me on my email address found below.

Thank you very much for your cooperation

<p>If you want more information about joining the Citizen Science Project you can contact Jessica Carr at: jess.carr@open.ac.uk</p> <p>Or her supervisor Jane Seale at: jane.seale@open.ac.uk</p>	 
--	---

Appendix F – Examples of offline resources

1) Definitions of key phrases:

What is a citizen?

A person who is part of a community (e.g a citizen of the learning disabled community, or a citizen of the scientific community)



What is citizen science?

Citizens doing science with scientists



What is research?

Helping communities, stopping problems and improving lives by answering questions



2) Survey responses – Put into question order and then printed off

How do we feed a Cat or a Dog?

Stick to a routine and ensure the animal has space to eat in peace

8/20/2019 3:29 AM Add tags - [View respondent's answers](#)

□ We put the food in a bowl. One per cat or dog and leave them to eat it in peace

7/12/2019 1:44 PM Add tags - [View respondent's answers](#)

□ With dog/ cat food 2-3 times a day in a bowl

7/12/2019 9:52 AM Add tags - [View respondent's answers](#)

□ Both cats and dogs need a complete diet.

7/11/2019 5:05 PM

What do you do if your Cat or Dog gets Bitten?

Clean the wound and take them to the vets

8/20/2019 3:29 AM Add tags - [View respondent's answers](#)

□ You should take your dog/ cat to the vets to get medical attention.

7/12/2019 1:44 PM Add tags - [View respondent's answers](#)

□ Check them for puncture wounds/ bleeding/ swelling and take them to the vets

7/12/2019 9:52 AM Add tags - [View respondent's answers](#)

□ Ring your local vet

7/11/2019 5:05 PM

Appendix G: Reflective letter from MLMC staff member

Citizen Science Project

My Life My Choice Banbury Group

Jess and I first spoke in April 2018 about the possibility of her coming and working with one of our monthly Self-advocacy Groups as part of her PhD on Inclusive Research. The aim was to work alongside some of our Members in order to bridge the gap between inclusive research and citizen science. This was of great interest to us, as several of our MLMC Members and myself had already been involved as participants in a previous study, “Doing research inclusively, doing research well?” in 2012 (Melanie Nind and Hilra Vinha).

After speaking with Jess and seeing all of the comprehensive material she had prepared outlining her project, we felt that it would be a good idea for her to work alongside our Banbury Group. This Group has been running for 10 years now and it is one of our longest running self-advocacy meetings. Some of our Group Members have gone on to become Trustees of My Life My Choice (MLMC) and over the years have been heavily involved in campaigning to improve the lives of PWLD, so this felt like a good project for them to work on. Three of the Banbury Group Members had taken part in the 2012 study and Jess had her first session with the Group early in 2019. During this first session we explored the meaning of Citizen Science and Jess took the Group Members through the process for consent. It was

clear from the outset that Jess was working *alongside* the Group Members. Their thoughts and ideas were taken into account from the very beginning. Over my past two decades of working in the field of Learning Disabilities, I have reflected on the occasions where I have witnessed PWLD having things done *for them*, without necessary being involved in the process themselves. It was this which led me to working within the Self-advocacy movement. I was struck from early on at the scope and choice the participants were given in terms

of making decisions about how the project evolved, but also the pace and materials were well matched to their individual wants and needs. This is not an easy balance to strike, so I have much respect for Jess in achieving this. Even more so, as the range of differentiation within the Group is quite wide and therefore, designing activities that appealed to all of those taking part would have also been somewhat challenging.

It has been a pleasure and a privilege to see the project unfold over the past year. I have very much enjoyed having Jess in the sessions, working alongside her and our Members. Personally, I have valued the project immensely and learned an awful lot along the way. Jess

has certainly become a *Member of the Group*! It is a shame that we have had to end quite so abruptly because of the current pandemic, but I know that Jess has gone out of her way to be as accommodating as possible for our Members in this final phase, in order that we might see it through to the end. Going forward, I really do hope that this study furthers the important cause of true and proper inclusivity of PWLD in research.

Session Facilitator, MLMC Banbury Group

June 2020